

# Challenges in parenting a child with autism spectrum disorder

*A study among 15 parents with ethnic Norwegian and ethnic minority background*

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## **Abstract**

There are a number of challenges parents face parenting a child with autism spectrum disorder. The challenges lay in different spheres of life: getting used to the diagnoses and having realistic plans for the future, economic concerns, social contacts, cooperation with professionals, daily routine. The major purpose of this study was to identify challenges in the spheres of cooperation with different professionals and social contacts that parents face while raising a child diagnosed with autism spectrum disorder.

The theoretical basis for the study is viewed from the perspectives of parenting a child with autism spectrum disorder, coping and social support systems approach.

Within the framework of a quantitative approach, a questionnaire has been used to collect the data from fifteen parents.

The study has revealed that the 15 parents of children with autism spectrum disorders did have access to cooperation with professionals within health, educational and psychological services, as well as some social contacts. Challenges they faced included problems related to time it took to get the services, access to professional support and satisfactory social network. On the other hand many parents experienced as a motivating factor the emotional support professionals gave them. Parents with ethnic minority background and with multiple children with special needs seemed to experience less satisfactory cooperation with professionals and also had less acceptable social network.



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# 1. Chapter 1 Introduction

This paper is the result of a theoretical and empirical study of the challenges parents of a child with autism spectrum disorder face. The challenges parents of children with autism spectrum disorder meet may lie in various spheres of life. Among these are: getting used to the diagnoses and having realistic plans for the future, economic concerns, social contacts, cooperation with professionals, daily routine, etc. These spheres are broad and it will not be possible to focus on all of them in one master's study. The present study looks specifically at the challenges parents of children with autism spectrum disorder face when cooperating with professionals and social contacts.

One of Oslo's special SFOs (after school activities) for children with autism spectrum disorder has been my working place for two years. Out of seven children with autism spectrum disorder there, only two have two ethnic Norwegian parents.

## 1.1 Research problem and research questions

*The topic of this master's thesis* is challenges parents of a child with autism spectrum disorder face, and will focus on parents' cooperation with different professionals and on the sphere of social contacts. Additional interest of the focus lays in challenges ethnic minority parents may face in the areas of cooperation with professionals and social contacts.

The *research problem* of the study is as follows:

What challenges in the spheres of cooperation with different professionals and social contacts do parents face while raising a child diagnosed with autism spectrum disorder?

This study has tried to identify parents' experiences of what has been functioning, as well as what they have experienced as less satisfactory in the fields of cooperation with professionals and social contacts.

The research problem can be further broken down into the following *two research questions*:

Research question 1: What are the wishes and experiences of parents who have a child with autism spectrum disorder in the sphere of cooperation with different professionals? Are there any differences between the wishes and experiences of ethnic minority parents and ethnic Norwegian ones?

Research question 2: What are the wishes and experiences of parents who have a child with autism spectrum disorder in the sphere of social contacts? Are there any differences between the wishes and experiences of ethnic minority parents and ethnic Norwegian ones?

A number of studies in the field of ethnic minority parents with children who have disabilities have been conducted in Norway. Among these, the ones done by Sørheim (2000) and by Mikkelsen (2005) are of special interest for my paper. No studies, from the ones I found, however, focus specifically on ethnic minority parents dealing with children with autism spectrum disorder, which makes it an additional interest in the focus of this thesis.

In this paper, "*ethnic minorities*" refers to:

I meldingen omtales ulike 'minoriteter', både etniske, religiøse og språklige mindretall som skiller seg ut fra 'majoriteten'. Folkerettslig er det ulike former for minoritetsrettigheter, både individuelle og kollektive. Mange med innvandrerbakgrunn velger å se seg som del av en minoritet, mens andre ikke oppfattes slik, verken av seg selv eller omgivelsene. Fordi ikke alle etniske minoriteter i Norge har innvandrerbakgrunn, og fordi tilknytning til Norge og rettigheter varierer, er det vanskelig å anvende minoritetsbegrepet som en fellesbetegnelse for alle som ikke tilhører 'majoriteten' (Stortings melding Nr 17 1996-97).

The main point in the quotation above is that "ethnic minority" is defined as an ethnicity that doesn't belong to a majority. The following explanation is given there:

because not all ethnic minorities in Norway have immigrant backgrounds and their attachment to Norway and rights vary, it is difficult to apply the “minority” term to everyone who doesn’t belong to a “majority.”

## 1.2 Clarification of concepts

Main theoretical concepts used in the thesis are: *challenge*, *autism spectrum disorder*, *cooperation*, *professionals* and *social contacts*.

*Challenge* refers to a demanding or stimulating situation (Sinclar & Hanks 1987, Olsson 2004, cited in Weldeab 2006, p.6). It is also defined as including both the difficult and motivating experiences of parents (Weldeab 2006). Parenting a child with autism spectrum disorder, as well as the child with intellectual disabilities, has both negative and positive impacts on family life, e.g. having to adopt new ways of life (Olsson 2004). In the present study the focus is on both *difficulties* and *problems* parents face, as well as *motivating factors* in the areas of cooperation with professionals and social contacts.

The next central concept is *autism spectrum disorder* and it refers to:

Although there is a broad range of cognitive, linguistic and adapting functioning across the autism spectrum, impairments in social understanding, emotion perception and pragmatic communication are universally present. Currently there are several ASD subtypes recognized by the principal diagnostic systems, the DSM-IV, and the ICD-10, namely autistic disorder, disintegrative disorder, Rett disorder, Asperger’s disorder, and PDDNOS (Zager 2005, p.38).

The concept of *autism spectrum disorder* is used in this paper in order to indicate that there are a number of disorders, in addition to autistic disorder, that involve impairments in social understanding, emotional perception and pragmatism.

The third concept, *cooperation*, refers to parents and professionals working together for a shared purpose. This type of cooperation is described by O’Brien & Dagget (2006) in the following way:

Together, parents and professionals can identify the child's most immediate learning goals and develop a way of tracking change once an intervention begins. Together, professionals and parents are more likely to succeed in the ultimate goal of providing effective services to children with ASD (O'Brien & Dagget 2006, p.214).

The term *professionals* in this paper refers to persons working within health, social, educational, child care and welfare services, and includes kindergarten teachers, regular teachers, after-school teachers, medical doctors, psychologists and other assistant personnel.

Concerning the last central concept, *social contacts*, Hallahan & Kaufman (1991, p.477) define it as "...informal source of support, such as the extended family, friends, neighbors, and church groups". For the purpose of this thesis, *social contacts* will be narrowed to friends and extended family, such as grandparents, uncles and aunts, cousins etc.

### 1.3 Expectations for the study

I had some expectations for the study based on previous research and my experience of working in the field as cited below.

*Expectations regarding cooperation with professionals:*

- Ethnic minority parents might experience more difficulties in cooperation with professionals. Previous studies done by Sørheim (2000), Beresford (1995), Hatton, Azmi, Caine & Emerson (1998), Nordby (2000) indicate that there is a difference in cooperation with professionals between ethnic minority parents and ethnic majority parents. Families with disabled children have much in common, but ethnic minority parents experience more difficulties in cooperation with professionals. Language and availability of services are possible reasons for those difficulties.
- Mothers might experience more difficulties in cooperation with professionals than fathers. Discussing gender differences in parents of ethnic minority backgrounds

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(Sørheim 2000) indicates that mothers with disabled children are marginalised both as ethnic minority women and as mothers of a child with a disability.

- One-parent families might be more dependent on cooperation with professionals. It would be logical to expect that, alone, a parent is more dependent on the cooperation with the professionals than two-parent families. Therefore, the different answers from one-parent families and two-parent families were expected even if I did not manage to find any specific previous research on this topic.

- Parents of multiple children with social needs might cooperate more with professionals. I expected to get different answers about cooperation with professionals from parents of more than one child with special needs than from the parents with only one child with special needs. I expected that parents of multiple children with special needs would cooperate more.

*Expectations regarding social contacts:*

- Minority parents might have fewer social contacts than ethnic Norwegians. Previous research indicates that ethnic minority parents will mostly have contacts with their fellow countrymen and family members. A study done by Sørheim (2000) shows that very little is done to make ethnic minority parents of disabled children meet others in the same situation. According to Bloom (Bloom 1998, cited in Nordby 2000), more ethnic minorities than ethnic Norwegians reported feeling alienated when asked about social contacts.

- Two-parent families might have more contact than one-parent families. I expected two-parent families to have more time for a social life outside the family.

## 1.4 Justification and significance of the study

*A significant number of people involved:*

According to Autismeforeningen: "Research shows that occurrence of persons diagnosed within autism spectrum is approximately 3-5 pr. 1000 inhabitants and more

frequent for the boys.”(Autismeforeningen i Norge 2008). There is no exact number on how many people are diagnosed within autism spectrum in Norway, but due to the fact that the population of the country is approximately 4, 6 million people, it comes to 14.000-23.000 people. The number of those directly involved in caring for persons with autism spectrum disorder is much higher and include families, friends and professionals.

*More knowledge can help to improve cooperation:*

Autismeforeningen highlights that “Professionals and helping officials have often little knowledge about the group” (Autismeforeningen i Norge 2008). Studies such as the present one may contribute to society’s and professionals’ awareness and acknowledgement about the wishes and experiences of parents of children with autism spectrum disorder and thus improve the possibility for cooperation.

*More information about how ethnic minority parents experience the situation may increase the possibility for improved cooperation and social contacts:*

The findings of the study may serve as a basis for future studies of ethnic minority parents with children with autism spectrum disorder.

## 1.5 Organization of the thesis paper

This thesis has five chapters. The content of each chapter is briefly presented below.

Chapter 1 contains the research problem and research questions, clarification of the main concepts, my expectations for the study, and justification and significance of the study.

Chapter 2 looks at previous research done in the field of parenting an autistic child, coping and social support systems approach.

Chapter 3 describes the methodology of the study. It starts by presenting design and instrument. The process of making the questionnaire is described. Parents’ comments on the questionnaire are highlighted as well. The chapter also contains a presentation

of the process of recruitment and my reflections on the number of parents I was actually able to recruit . Data collection and organisation are described in this chapter. At the end of the chapter, validity, reliability and ethical considerations are presented.

Chapter 4 contains the data presentation and analysis. It starts with demographic information about the parents, and then analysis of parents' answers is presented. The presentation of answers follows the logic of the questionnaire. The answers of parents as a group are given first, followed by the presentation of differences within the group according to background variables.

Chapter 5 gives a discussion of findings, conclusions and suggestions for the study.

The thesis concludes with the references for the study and the appendices.





## **2. Chapter 2 Theoretical Background**

This chapter includes a presentation of three sub-themes which may be central for understanding the challenges parents face in parenting a child with autism spectrum disorder. The concept of the challenge is presented in Chapter 1 and is reflected in all the three sub-themes, which are: Parenting a child with autism spectrum disorder (2.1), Coping (2.2) and Social support systems approach (2.3). At the end of this chapter a tentative model is presented (2.4), where I have structured my own understanding of some of the challenges parents meet.

### **2.1 Parenting a child with autism spectrum disorder**

The sub-theme of parenting a child with autism spectrum disorder is broken down further into four topics: the term “family” (2.1.1), families with disabled members (2.1.2), definition of autism spectrum disorder (2.1.3) and families with a child with autism spectrum disorder (2.1.4).

#### **2.1.1 The term “family”**

Different meaning is given to the term “family” in different cultures, religions and by different authors. There is no unified one. According to Beirne-Smith, Ittenbach & Patton (2002, p.470) “...the concept of family implies a combination of immediate and distant relatives who, through birth, adoption, or marriage, come to live together for extended periods of time”

Families tend to have different functions in different traditions and cultural perspectives. The four main functions concerning families including a member with a disability are given by Beirne-Smith et al. (2002). These are financial, medical, physical and socio-emotional functions.

There is variation within these functions. For example, consider the financial function’s aspect of the cost required by extra day-care or baby-sitting. In Norway

part of the cost (depending on the disability of the child) is covered by the state and is called “avlastnings tilbud”, while in Eastern European countries (e.g. Ukraine, which is my home country) all the costs for such care must be covered by the parents.

### **2.1.2 Families with disabled members**

The child’s disability, its type and severity plays an important role on how parents are affected (Hornby 1995, Beirne-Smith et al. 2002). The family unit has to adapt to the life-style of its member with disability as much as to life-styles of its other members, e. g. the daily routine of a child with autism spectrum disorder requires that parents plan every activity of the day carefully and often requires discussion beforehand. Parents may face many different challenges in adapting to this, such as restrictions of their own time for leisure activities, dealing with the child’s disruptive behaviour etc. Such families are often committed to a life-style which differs a lot from that of families without members with disabilities; they are often not able to leave a child with disability at home alone and have to ask for help. It means that they need different services to help them to live as independently as possible.

### **2.1.3 Definition of autism spectrum disorder**

Autism spectrum disorder, being a “hidden disability”, is not as easy to see as for example a disability which displays itself physically (such as cerebral Palsy, blindness and so on). First, the definition and clarification of autism spectrum disorder needs to be given. According to Autism Society of America:

Autism is a complex developmental disability that typically appears during the first three years of life and affects a person’s ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a "spectrum disorder" that affects individuals differently and to varying degrees. There is no known single cause for autism. (Autism Society of America 2008)

In a study by Zager (2005) the following definition of autism spectrum disorder has been given:

Although there is a broad range of cognitive, linguistic and adapting functioning across the autism spectrum, *impairments in social understanding, emotion*

*perception* and *pragmatic communication* are universally present. Currently there are several ASD subtypes recognized by the principal diagnostic systems, the DSM-IV, and the ICD-10, namely autistic disorder, disintegrative disorder, Rett disorder, Asperger's disorder, and PDDNOS (Zager 2005, p.38)

Educating possibilities will depend on the level of development of any particular child. According to autism Society of America (2008):

Educating children with autism is a challenge for both parents and teachers. These children are individuals first and foremost with unique strengths and weaknesses. Some may be of average to above-average intelligence, while others may be below average. Academic goals need to be tailored to that individual's intellectual ability and functioning level. (Autism Society of America 2008)

#### **2.1.4 Families with a child with autism spectrum disorder**

Having a child with autism spectrum disorder is a challenge for the whole family.

Gray (2002) underlines:

The pattern of family adaptation to autism describes a difficult process for parents. On the positive side, it involves the surmounting of early crises and the gradual adaptation of the family to the experience of living with a child with autism. On the negative side, it reflects the tenacity of the disability and its long-term effects on the family (Gray 2002, p. 216).

The family's psychosocial adaptation to autism spectrum disorder is an important issue, as well as how they cope and what role cooperation with different professionals plays in their coping; this is a main focus in this thesis. Gray (1993) gives several reasons why cooperation with different professionals is of special importance. First, autism spectrum disorder is an extremely disabling disorder which causes problems with language, destructive behaviour, violation of norms concerning eating and toileting. It puts a serious challenge on families' everyday life and their social relations. Second, there is no cure for autism spectrum disorder. Finally, parents of children will have a long-term involvement in the cooperation with different professionals due to the first two reasons. The combination of the severity of autistic symptoms and the absence of any reasonable prospect of a cure defines the difficulties in the relationships between professionals and parents.

Another focus of the thesis is in the sphere of social contacts. Previous studies show the role of the social contacts in the family's wellbeing. As pointed in Bromley, Hare, Davison & Emerson (2004) levels of reported distress are associated with high levels of child behaviour problems and a low level of informal support within the family:

Over half of mothers (from 68 participated in the research) screened positive for significant psychological distress and that this was associated with low levels of family support and with bringing up a child with higher levels of challenging behaviour. (Bromley et al. 2004, p.409).

## 2.2 Coping

Autism spectrum disorder, being a severely disabling disorder, may bring different stress factors to the family. The most common problems parents face when parenting a child with autism spectrum disorder are the child's lack of normal language, anti-social and sometimes aggressive behaviour, problems with eating and toileting, and tantrums (Gray 1994; Dunn, Burbine, Bowers & Tantleff-Dunn 2001). Caring for a disabled child places many extra demands on parents (Beresford 1995), including the duration of the period of treatment for a child with autism spectrum disorder and difficulties regarding prognosis and diagnosis. These add significantly to the parents' stress.

There are different definitions of coping. The one given by Beirne-Smith et al. (2002, p.476): "...a family's collection of overt and covert strategies for responding to life's difficulties". Another definition is given by Folkman (1991, cited in Weldeab 2006, p.59): "...a dynamic process which is changing thought and acts that the individual uses to manage the external and/or internal demands of a specific stressor – environment transaction that is appraised as stressful".

In this chapter the sub-theme of coping is presented with four additional topics: process model of stress and coping (2.2.1), coping through the use of services (2.2.2), coping through family support (2.2.3) and positive factors in coping (2.2.4).

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### 2.2.1 Process model of stress and coping

When discussing coping, the process model of stress and coping by Lazarus and Folkman (1984) should be mentioned (described in Beresford 1996). The model underlines that “...the process of coping mediates the effects of stress on an individual’s well-being” (Beresford 1996, p.31). It describes two key aspects of the coping process: coping resources and coping strategies. *Coping resources* refer to: “social and personal factors that determine whether an individual regards an event or situation as stressful, and the ways in which a stress can be resolved or managed”(Beresford 1996, p.31). Resources would include practical resources, social support and financial support. *Coping strategies* refer to “...the actions and thoughts a person uses to deal with a stress” (Beresford 1996, p.31). Coping strategies concern the mastering or managing the stress, as not all stress is possible to solve.

A variety of coping strategies are used by parents such as use of available services, family support, religion, individualism and others. Gray (1994) underlines that no single strategy is significantly better than the others, but use of services and family support are shown to be the most successful. The important role of services in supporting parents is underlined by Beresford (1996) as well. Two main focuses of this thesis concern the use of services and family support.

Most families develop a series of coping strategies (probably different strategies at different stages of child’s development), as many children with autism spectrum disorder will stay with their families over a long period of time.

Different coping strategies and mechanisms are described by different authors (Gray 1994, Beresford 1996, Dyson 1997, Hastings et al. 2005). They all have in common the fact that families need to restructure their daily life and adapt to the needs of their child. Gray (1994) structures the strategies into three groups: the ones used to cope with daily problems and public reactions to child’s disability (especially tantrums in autism spectrum disorder); the strategies designed to cope with the stigma of

disability; and finally the ones which focus on the problems resulting from living with autism spectrum disorder.

Summed up, parents with children with autism spectrum disorder seem to use different techniques and strategies to cope with different problems. They tend to use everything that works for them.

### **2.2.2 Coping through the use of services**

Getting help from different professionals is one of the most used and, as noted earlier, one of the most successful strategies. Dunn et al. (2001, p.40) call a social support a “buffer against stress”.

It is important that parents have information both about the diagnosis and about the services available. Information enables parents to demand appropriate services for their child (Beresford 1996).

A study conducted by Gray (1994) shows three main advantages of using services from a parents’ perspective. First, the skills gained by the child with the help of different professionals often make family life easier. Second, help of professionals is available to provide respite for over-stressed families; this varies between several hours per day in a treatment centre up to some days in a respite care-centre. Third, professionals provide reassurance for parents in order to help them in times of crisis.

According to Beresford (1996), a child’s difficult behaviour is the main factor why parents seek professional help. Parents report using different strategies suggested by professionals such as not reinforcing bad behaviour and the withholding treats.

### **2.2.3 Coping through family support**

Family support is combined with professional support in terms of success and importance according to Gray (1994). Two ways of support should be named when it comes to helping families to cope with their stress: emotional support and providing

different activities that would help a family to be as independent as possible. Gray (1994, p.287) refers to the second one as “helping families to live as normal life as possible”, explaining that for many of the families their social life centres on the child with autism spectrum disorder and they become socially isolated.

Most parents try to have interests beyond the family life such as spending time with friends, having a hobby etc. Maintaining these outside interests would require having help caring for the family, either from their spouse or someone from their extended family.

The types of stress parents experience are unique to them, which may make coping problematic. Finding one strategy which works for all families is not possible and not important. It is important that a family finds a combination of coping strategies which allows them to be happy with their families.

#### **2.2.4 Positive factors in coping**

The negative aspects of stress in parenting a child with autism spectrum disorder have to be balanced by some positive factors in order to make it possible for families to live with their member with autism spectrum disorder. Beresford (1996) names two positive factors: the parent-child relationship and the ways that parents cope with the stress. The ways of coping with the stress have been described above, so some words should be devoted to the parent-child relationship. It is usual that parents tend to search for the best services for their children (in terms of education, therapy, psychological services etc), but there may be a certain stigma when it comes to the parent-support services. Most parents put the needs of their child in front of their own needs; this is why the main function of all the services should be to maintain the parent-child relationship (Beresford 1996).

Professionals may significantly support parents' methods of coping. According to parents who participated in a study done by Beresford (1996), parents point out two

ways this can be done: by being honest about the child's condition and realistic when it comes to the prognoses, and by the availability of information and counselling.

It follows from this that it is very important that the cooperation with parents does not serve as an additional stress factor for the parents.

## 2.3 Social support systems approach

The sub-theme of social support systems approach contains two topics: cooperation with different professionals (2.3.1) and social contacts (2.3.2).

Three approaches in understanding families are the social support systems approach, family systems theory and the ecological systems theory. In this theoretical presentation the focus is on a *social support systems approach*. This approach highlights education and treatment not just for the individuals, but rather for the broader social context. "The core idea of the social systems approach is the social system influences the family's ability to fulfill the needs of the child with disability" (Weldeab 2006, p.52).

This approach points to two important issues: informal support plays a significant role in the families' life, and that the main function of social support is "helping families help themselves" (Hallahan & Kaufman 1991, p.463). The same study underlines that the main aim of this help will be building independence from a traditionally dependent parent-professional relationship.

One form of social support is a parental support group comprised of parents who have children with the same disabilities. These group meetings may have both a formal (e.g. organised every week with the help of professionals, of giving lectures by professionals on a specific topic) and an informal nature. It is up to parents themselves to decide how often they want to meet. The main idea of these meetings is to share experiences and learn from each other.



Seligman and Darling (1989, cited in Hallahan & Kaufman 1991, p.469) name four main benefits of such groups: 1) alleviating loneliness and isolation, 2) providing information, 3) providing role models, and 4) providing a basis for comparison.

### **2.3.1 Cooperation with different professionals**

The terms “cooperation” and “collaboration” are often treated as synonymous. In Cambridge Dictionaries On-line (2007) *cooperate* means “to act or work together for a shared purpose, or to help willingly when asked” and *collaborate* refers to “work together or with someone else for a special purpose”.

In the present study parents and professionals have a shared purpose, namely to support the development of the child. For this reason, I have chosen to use the term “cooperation” in this paper.

Professionals empower parents to actively participate in decision making. It is completely up to parents to decide how much power they want to have in the process. Some families allow professionals to make the most of the decisions, while the others want a shared role in this process. Gray (1993, p.1046) discusses three cornerstone questions in cooperation between parents of autistic children and professionals: the possibility of a cure, the question of the child’s affectionate nature, and the uniqueness of the child and how this relates to the possibility of institutionalisation and adds that “Because of the absence of a biological marker for autism, the possibility for an alternative interpretation by the parents always remain open” Gray (1993, p.1046). Professionals do not give optimistic prognoses for the treatment of autistic children, as there is no possibility for the recovery of autism spectrum disorder. “This combination of the severity of autistic symptoms and the absence of any reasonable prospect of a cure means that parents and the treatment centre staff are likely to experience prolonged and difficult relationship” Gray (1993, p.1046)

#### **a) Professional support**

The importance of social support for families with members with disabilities has been underlined by many researchers (Beresford 1996, Gray 2002, Hallahan and Kaufman 1991). According to Agosta and Melda (1995):

To most people, “family support” means providing families with whatever it takes for families of people with disabilities to live as much like other families as possible. More specifically, family support can include supports, resources, services and other assistance....The help offered can include service coordination, a wide array of goods and services, and financial assistance (Agosta and Melda 1995, p.271).

The support is given on different levels starting from local services available at the community level up to services provided by the state as well as by different agencies covering different spheres of life such as medical care, education, psychological services etc.

There are many public agencies parents have to deal with to be able to get the help they need. Local municipalities, schools, and hospitals are just few of them. Often families have to negotiate simultaneously with different agencies which do not have a clear agreement among themselves. This can be a frustrating experience (Agosta & Melda 1995). The availability of services is a key issue when discussing professional support. Konstantareas (1991 cited in Siklos and Kerns 2006) points out that it is not only the number of support structures that should be considered when discussing the influence of supporting agencies on healthy adaptation in families with children with autism spectrum disorder, but more the quality of the support.

#### **b)Parental involvement in the process of cooperation**

Parents’ willingness to participate in cooperation with professionals plays a crucial role for the benefit of cooperation. Often parents are eager not only to share their information and experiences in dealing with their child, but are also eager to implement school teaching at home. The cooperation may be viewed as a frustrating one from both sides, as teachers may think that the parents do not want to listen to their advice or vice versa. When it comes to the professionals “...they must respect parents’ right to make the decision in consideration of the wider needs of their families.”(Hornby 1995, p.25)

According to Swap (1993, cited in Hornby 1995) parental involvement in facilitating a child's development should be supported by the professionals. The level of the involvement varies from just being updated on a child's progress to being a child's tutor at home. The tutoring option is shown to be the most productive by Swap.

### **c)Emotional support**

As Herington and Blechman (1996, cited in Beirne-Smith et al. 2002, p.475) have suggested, "...there is no easy way of identifying which families are at the greatest risk, how to reduce the risk of overwhelming stressors, or how to return to optimum levels of functioning once their development is hindered". This is where the importance of emotional support from professionals comes into the equation. It is not enough just to give professional support; professionals need to develop empathy and understanding concerning the needs of families with a child with autism spectrum disorder. While professionals have shifts working with the child with autism spectrum disorder, it is a 24-hour-a-day job for the parents. "They (teachers) need to be patient when dealing with parents' anxieties concerning their children and in encouraging parents to develop their children's independence and relationship outside the family" (Hornby 1995, p.64).

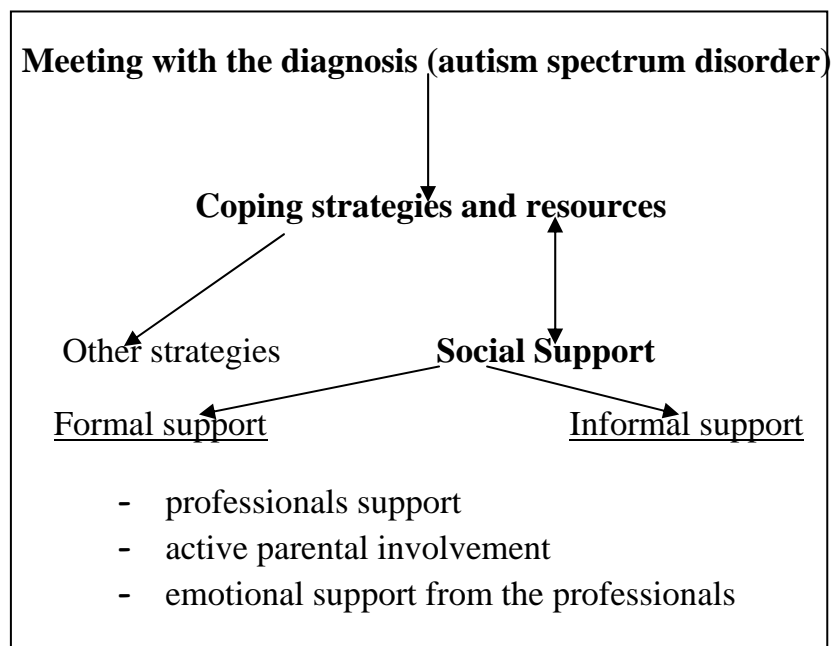
## **2.3.2 Social Contacts**

Social support can also have an informal nature. While the formal support is provided for by the different professionals such as kindergarten teachers, regular teachers, after-school teachers, psychologists, medical doctors and other assistant personnel, the informal support is given by family members (as well as by members of extended family) and friends. Agosta & Melda (1995, p.276) emphasize the importance of informal support: two premises underlie an emphasis on "natural resources: a) the resources available from the formal support system are too limited to meet the full range of family need and b) the belief that supports are most effective and least costly when their source is closest to the family, both geographically and personally." Family structure has a direct impact on the cooperation with

professionals, because it doesn't only include the interaction among the family members, but also the interaction with others outside the family (Hallahan & Kaufman 1991). Some cultures will include many more members in the family than just parents and children, such as aunts and uncles and grandparents. This makes it difficult for ethnic minority families to have informal support in Norway while their "family members" are in the country of their origin.

## 2.4 Tentative model

In my understanding of the field "challenges in parenting a child with autism spectrum disorder", parents go through three main stages: 1) *meeting with the diagnosis*, 2) *coping* and 3) *social support*. In the figure below I have tried to illustrate my thinking regarding the challenges in parenting a child with autism spectrum disorder.



**Figure 2.1 Tentative model of challenges in parenting a child with autism spectrum disorder**

The challenges are present at all stages. In the first stage, parents meet with the diagnosis and get more information about autism spectrum disorder and its ramifications. Challenges in this stage are not the focus of this present study. The second stage will include coping with autism spectrum disorder and adjusting the

ways of family life. Social support, as the third stage, will be combined with other coping strategies which parents choose for themselves. The reason why social support is the only coping strategy which stands separately as a stage of the process because of its permanence. By this I mean that other strategies may be chosen, but social support will be present in the life of most families regardless of circumstances. Parents have to cooperate with professionals working with their child. In addition parents often ask for informal support from family and friends. Social support may be subdivided into *formal* (professional support, parents' involvement in cooperation process and emotional support from professionals) and *informal support* (from family members and friends).



### **3. Chapter 3 Method**

The main purpose of this study is to find out what kind of challenges parents may face in parenting a child with autism spectrum disorder in the spheres of cooperation with professionals and social contacts. In this chapter the following topics are presented: design, instrument, target population and sampling, process of data collection, data treatment, validity and reliability, and ethical considerations.

#### **3.1 Design**

This study follows a quantitative approach and a survey strategy. Gall, Gall and Borg (2003, p.23) define quantitative research as: "...grounded in the assumption that features of the social environment constitute an independent reality and are relatively constant across time and settings." They specify that the approach develops knowledge by collecting numerical data on opinions of the samples and then subjecting the data to numerical analysis. The survey strategy is used to collect data about characteristics, knowledge or opinions in a population or sample population (Gall et al. 2003). The present study aims at getting parents' wishes and experiences upon the challenges they face in parenting a child with autism spectrum disorder. The survey, according to Gall et al. (2003, p.223) "...collects data from a sample that has been selected to represent a population to which the findings of the data analysis can be generalized". De Vaus points out that survey is often described as "...being sterile and unimaginative but well suited to providing certain types of factual, descriptive information – the hard evidence" (De Vaus 2002, p.5).

The design of this study may be regarded as a partly correlational. "The essential feature of the data is that one observation can be paired with another observation for each member of the group....Correlation is concerned with describing the degree of relation between variables" (Ferguson 1966, p.105). The advantage of this design is given by Gall et al. (2003) ".....enable researchers to analyze the relationship among

a large number of variables in a single study”. The relationship between background variables (e.g. ethnicity, education) and variables concerning cooperation with professionals and social contacts has been focused on in this particular study. In order to realize it, bivariate analysis was conducted. De Vaus (2002, p.356) defines it as “...a general category of analysis in which two variables are analyzed simultaneously in order to examine the relationship between the two variables”

Among central characteristics of the survey is the great number of participants, and representative sampling of participants. The present study planned at including at least 40 parents of the target group. As described below (see 3.3) the number of participants was dramatically reduced.

I planned on conducting three- four follow up interviews, but due to the time restrictions and low interest from the parents, interviews were not included in the study.

## 3.2 Instrument

According to Gall et al. (2003), due to the questionnaire’s standardized, highly structured design, it’s compatible with the quantitative approach of the research.

### 3.2.1 Development and content of the questionnaire

The questionnaire I made is inspired by the Family Needs Questionnaire (FNQ) made by Siklos and Kerns (2006). According to Siklos and Kerns,

Although the FNQ has been used primarily with parents of individuals with Traumatic Brain Injury (TBI), many of the cognitive, behavioral and emotional disturbances in children with TBI are similar to those of individuals with Autism Spectrum Disorders (ASD) : both groups may exhibit disruptive, often embarrassing behaviors; both groups may show mild to profound intellectual impairments; and both groups may exhibit mild to significant impairments in social functioning (Siklos and Kerns 2006, p. 924)

The quotation refers to the reason why parents of children with TBI and ASD report similar feelings. The questionnaire made by Siklos and Kerns (2006) is based on six



factors: health information, emotional support, instrumental support, professional support, community support network, and involvement with care. Items from two of the factors have been adapted and included in my questionnaire: emotional support and professional support. In addition my instrument includes topics concerning background information, parental involvement in the process and social contacts (see Appendix 8 for the full text of the questionnaire).

*Summed up the construction of my questionnaire is as follows:*

**Table 3. 1 The construction of the questionnaire**

Variables/sub-variables	Number of Items
<b>Background information:</b>	(No 1-12)
-concerning the family	7
-concerning the child	5
<b>Cooperation with different professionals:</b>	(No 13-47)
-professional support (23)	23
- parental involvement in the process	5
-emotional support from the professionals	7
<b>Social contacts:</b>	16(No 48-63)
<b>Open question about the whole questionnaire</b>	(No 64) 1

## Scaling

The questionnaire contains totally 64 questions. Twelve of them ask for background information. For items 13 till 63 three different types of scales were used, two of which were inspired by the Siklos and Kern's questionnaire (2006). For the questions aiming at asking about parents wishes/needs Likert scale was used, described by de Vaus(2002, p.102) as “....providing a statement that reflects a particular attitude or opinion. Respondents indicate their level of agreement or disagreement with the statement.” Parents were given four alternatives: very important, rather important, rather unimportant and very unimportant. The middle alternative (undecided answer) was not included in the scale in order to make parents decide the direction of their answers.

For items concerning experiences with both cooperation and social contacts an ordinal scale with the answering alternatives yes-partially-no was created. According to De Vaus (2002) it is a scale which allows to rank the variable from low to high. Parents were asked to rank to which extend they got different services, information etc.

The last scale aimed at getting information about parents' assessment of cooperation with professionals and had a multiple choice format, "...providing alternative attitude positions and asks which is closest to the respondents' own view" (De Vaus 2002, p.105). Parents were given the following answering alternatives: "I never contacted these professionals" / "I contacted these professionals and did not get help" / "I contacted these professionals and got help" / "I contact these professionals every time I need help from him/her".

The main reason for using three different types of scales was that questions aimed at getting information about three different areas: parents' needs and wishes, parents' actual experiences and parents assessment of cooperation with professionals.

### **Content**

As mentioned above the questionnaire had 64 items divided into three main variables: Background information, Cooperation with different professionals, and Social contacts.

- The variable "*Background information*" contained two sub-variables: information concerning the family and information concerning the child. In this part of the questionnaire parents were expected to give general information about themselves as well as information about the child diagnosed with autism spectrum disorder. General information included gender, age and education of the parents; age and health information about child as well as information about diagnose etc. (see Appendix 8 for more detailed information).

- The variable "*Cooperation with different professionals*" contained three sub-variables: professional support (23 items), active parental involvement in the process

(5 items) and emotional support from the professionals (7 items). In this part of the questionnaire parents were expected to evaluate the cooperation with different professionals as well as give information about professional support parents got (if any), parents' own involvement in the process of education /professional treatment of their child , and emotional support parents got from the professionals if any (see Appendix 8 for more detailed information).

- The variable "Social contacts" consisted of 16 items and contained information about parents' social network (see Appendix 8 for more detailed information).

### ***Language***

The instrument was originally made in English and needed to be translated to Norwegian. I did the translation myself, because I was the one who wrote the items in English and knew the meaning of each one. It turned out that none of the parents preferred the English variant (they had an opportunity to choose between English and Norwegian in the Informed consent), (see Appendix 4). I think it was useful to make it in English at first and translate it afterwards due to two reasons: the original questionnaire I got inspired by is in English and I can refer to the English variant of the items in my master thesis without any problems. The translation of the questionnaire was checked by both my Norwegian host family and my supervisor. All the language corrections given by them were taken into consideration and needed changes were made.

### **Norwegian Science Data Services approval of the questionnaire**

When the questionnaire was made I applied to the Norwegian Science Data Services (NSD) for the project to be approved and the permission to conduct the study given. The application to the NSD was sent on the 2<sup>d</sup> October 2007 and on the 7<sup>th</sup> November 2007 I received an email with the corrections/ additional information I had to make in order to be able to conduct the study. Among the corrections were:

- underline that the participation in the research was voluntary;
- write the date for the end of the project;

- underline that all the information would be deleted as soon as the project was over;
- the project was recognised by the commission for the privacy protection for research in NSD ( Personvernombudet for forskning ved Norsk samfunnsvitenskapelig datatjeneste);

NSD also recommended that the filled out questionnaires and the name list should be kept in two different cabinets which were locked. They also recommended removing the sentence about the promised anonymity of the answers, as the respondents could be recognised through the background variables.

All the recommended changes were made and on the 8<sup>th</sup> November 2007 the project was approved.

### **Pre-test**

As soon as the project had been approved I conducted a pre-test. Originally I planned on asking a family who had a child with autism spectrum disorder for help with the pre-test. They matched the aim of the study, as one of the parents was ethnic Norwegian and the second one belonged to an ethnic minority. I asked both of them to fill out the questionnaire separately and they refused. They explained that they did not agree with the diagnosis given to their child and they did not want anything that had to do with autism spectrum disorder. I then asked two teachers who had children themselves and who were working with children with autism spectrum disorders to answer the questionnaire and give me feedback on it. They kindly agreed to do so. The feedback I got from one of them was that the items: “Help in implementing Individual Education Plan goals should be given to me” and “Professionals should help me in implementing the school training at home” seemed similar and asked for the same information and I should consider deleting one of them. After discussing with my supervisor I did so. The second feedback contained some suggestion for correcting the word usage in the Norwegian variant and it was taken into consideration as well.

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### **Assessment of the questionnaire**

The questionnaire generally worked out for gathering the information I was aiming at.

#### *What I could have done differently:*

I probably should have included fewer questions on the theme of professional support, as some of them turned out to be not as informative as I expected them to be. In addition, I should have included follow-up questions for all the items as was the case for instance with Items 13&14(see Appendix 8).

#### *Parents' comments on the questionnaire:*

Under the last open-ended question parents were asked to give their feedback on the questionnaire. One of the parents evaluated the questionnaire as covering enough and did not have anything to add. Another parent commented that many of the questions were important for him/her.

Several of the parents suggested that the district authorities and social security offices should be added to the category of professionals parents cooperated with as they played an important role in parents' every day life. Another comment was that not all the questions were relevant for one of the parents as their child had 100% institution place (which I did not expect). Some of the parents replied that they did not know if they could answer correctly to all of the questions, indicating that the questions could have been more precise (applies to Items 28, 29), (see Appendix 8). Another suggestion was to go in depth about the time it took to establish the social contact net and the pressure parents got because of it. A reflection from another parent was that special professional support for the siblings should also be discussed.

## **3.3 Target population and sampling**

### **Population**

The purpose of the study is to focus on both ethnic minority parents as well as ethnic Norwegian parents who have a child diagnosed with autism spectrum disorder. The

Oslo region has been chosen as a geographical region due to two main practical reasons and restrictions: the time factor and financial resources, as I am a self-financed student. There are three other specific factors which make the Oslo region interesting for the current research: 1) the region focusing around the capital of the country would presumably make the access to different services easier for the parents of children with autism spectrum disorder; 2) the ethnic minority families are generally widely represented in the capital region, and 3) the high population of the region (in comparison to other regions of the country) would make a high representation of the families with children with autism spectrum disorder in general.

The named above reasons make the *population* of the study to be parents of children diagnosed with autism spectrum disorder in Oslo region.

### **Sampling**

Criteria for the sampling of parents were:

- they should have a child diagnosed with autism spectrum disorder
- the child should attend a special school or a school with special unit for children with autism spectrum disorder. The main reason why parents with school children were chosen as a focus group is that by the school age of the child parents would have some experience in cooperation with different professionals, even if a child was diagnosed at the age of three years (which is typical for children with autism spectrum disorders).

#### *Recruitment of the participants:*

By contacting the Autismforeningen in Norway by email I got a list with the names of all the schools in Oslo which had special units for children with autism spectrum disorder as well as the special schools. Out of ten schools in Oslo three gave positive response on my email to sending the invitation for the participation to the parents (cover letter & informed consent), (see Appendices 3 & 4). A special school for children with autism spectrum disorders was contacted by email and I got a positive response. This is how I ended up with four schools in total. In the schools I contacted

the headmasters and assistant headmasters by telephone. They made the decision whether a school was interested in participation and forwarded the information to the person responsible for the special groups. Approximately 70 invitations were given out to schools. The number is not exact, because each school had to be the ones to put the invitations for participation in a contact book of each child, I was not permitted to do it myself. I hoped for 40 participants. The 3d of January this year all together 15 parents had volunteered to be participants.

*Purposeful sampling:*

“In quantitative research, sampling refers to the process of selecting a sample from a defined population with the intent that the sample accurately represents that population” (Gall et al. 2003, p.167). Due to the restricted amount of the schools with units for autism spectrum disorders and just one special school, the sample of the research is not aiming either at representation of the population or its ability to generalise. The sample I used in my research has more similarity with the purposeful sampling, which is not typical for quantitative research

### 3.4 The process of data collection

After sending me the informed consent (see Appendix 4) on participation in research all the parent received the questionnaire by mail. The questionnaire was sent with a pre-paid envelop included with the return address of the Department of Special Needs Education.

In the mid of January I had only gotten seven parents' questionnaires back. Within the next three weeks I sent two reminder-letters with the questionnaire included (reminder letters may be viewed in Appendices 6&7). The last filled out questionnaire was received after approximately one and a half months.

### 3.5 The data treatment

The statistical analysis of data was done by using the Statistical Package for Social Sciences (SPSS) computer software for Windows.

Descriptive statistics was used for frequencies, percentages and correlation(Pearsons Chi-Square)).

The data from open-ended questions was analysed manually.

### 3.6 Validity and reliability

*Validity* is defined by De Vaus (2002, p.366) as "...whether the indicator measures the concept we say it does". Yin (cited in Gall et al. 2003) judges the quality of a case study by three types of validity: construct, internal and external. Two of them may be used for judging the quality of a survey as well. "*Construct validity* is the extent to which a measure used in a case study correctly operationalizes the concepts being studied" (Gall et al. 2003, p.460). De Vaus (2002) defines it as "... evaluating a measure by how well the measure conforms the theoretical expectations". By *external validity* Gall et al. (2003) mean the extent to which the findings can be generalized to similar studies. Only 15 parents participated in the present study, which means that findings from this study only describe wishes and experiences of the sample parents and cannot be generalized to other populations. It was difficult to get parents interested in the research and actually volunteer to answer. I think one of the reasons for this may be a great amount of surveys which is done in Norway. Parents are being contacted about different issues and asked to fill out different questionnaires. The second reason, in my opinion, is a great load of work parents have to do every day while parenting a child with special needs and to fill out a questionnaire they would need to have free time for it. And the last reason, which I consider, is that some parents may not believe in research and think that their filling out of the questionnaire would not change anything, so they do not answer it.



*Factors which could have enhanced the validity:*

The questionnaire for this research was inspired by Family Needs Questionnaire made by Siklos and Kerns (2006) as well as built on previous research done in the field, which was one of the ways to enhance its construct validity.

The pre-testing and checking the translation of the questionnaire by another person (see 3.2.1) were also ways of enhancing validity. The necessary adjustments were made after both the pre-testing and checking the translation.

*Factors which could have threatened the validity:*

The first one is the nature of sampling done. Parents who wanted all participated in the research.

The use of three different scales is the second one. This may have limited the answers even though the open-ended questions were included at the end of each sub-theme.

The absence of the middle alternative may also be considered as a threat to the validity. Parents had to decide for the direction of their answers even if they were not sure.

Due to the fact that I only got 15 answers, I was not able to make any correlation analysis such as factor analysis for example, which is considered as a way of securing the validity of interpretations by Gall et al. (2003).

Assessment of the questionnaire is also a validity concern which is described under the subchapter of instrument (see 3.2.2).

*Reliability* is defined by Yin (cited in Gall et al 2003, p.460) as “...the extent to which other researchers would arrive at similar results if they studied the same case using exactly the same procedures as the first researcher”.

*Factors which could have enhanced the reliability:*

Pre-testing and having a second person to check the translation were done. It helped to develop precise instructions for filling out of the questionnaire.

Coding for SPSS was double-checked after some days in order to avoid any mistakes.

As the instrument was made for the purposes of this research I consider the *factors* described above as a *threat to reliability* as well. The factors which threatened the validity would probably threaten the reliability as well.

### 3.7 Ethical considerations

It's important to take ethical considerations into account conducting a research with human participants involved.

#### *Informed Consent:*

According to Gall et al. (2003), informed consent is the information every participant must get "...about what will occur during the research study, the information to be disclosed to the researchers, and the intended use of the research data that are to be collected". In the present study parents got the information about the study in a cover letter (see Appendix 3) together with the Inform consent (see Appendix 4). The cover letter informed about the voluntary participation, possible withdrawal at any stage of research, confidentiality in data treatment and intended use of the data.

#### *The Norwegian Science Data Services consent:*

According to Robson (1999), researchers should ensure that relevant persons and authority have been consulted and informed and that the necessary permissions and approval have been obtained. In the current research the permission was obtained from principles of schools as well as from the Norwegian Science Data Services (NSD). In asking the principals for permission to contact the parents through the schools I had to show them the approval for the project given by the NSD and my Cover letter with the detailed information about the research.

#### *Parents of children with autism spectrum disorder as a vulnerable group:*

Having a country of origin in the background information made the questionnaire sensitive to the recognition when it comes to the ethnic minority families with

children with autism spectrum disorders since they are not that many in Oslo. It has been evaluated as an ethical consideration.

The research materials, e.g . completed questionnaires are only used for the purpose of the research and are going to be deleted as soon as the study is finished and the thesis has been evaluated.



## **4. Chapter 4 Data Presentation and Analysis**

The purpose of the study is to find out what kind of challenges parents with a child with autism spectrum disorder face in cooperation with different professionals as well as within their sphere of social contacts. The main goal of the results chapter is to show how the results illustrate the goal of the study. The respondents were 15 parents, both ethnic Norwegians and ethnic minority.

The chapter starts with the presentation of the background information on the participants (4.1.1) and some general information on their children with autism spectrum disorder (4.1.2). Afterwards, data is presented on parents' opinions on the cooperation with professionals (4.2) and on parents' views of their social contacts (4.3).

The questionnaire data of the teachers was analyzed quantitatively using the Statistical Package for Social Sciences (SPSS). The presentation of the data is in a tabular format showing frequencies and percentages of the responses. There is a brief discussion on some of the items.

The demographic data of the parents and their actual situations, as well as more detailed information on their children with autism spectrum disorder, is important information prior to seeking the parents' opinions on their cooperation with the professionals and their perception of the social network. The data makes it possible to know the characteristics of the respondents and their family situations.

All parents of children with autism spectrum disorder are the population of the study. The best for the study would be to have a sampling which would be possible to generalise statistically. It has not been possible for me to conduct the representative sampling for the population out of practical and economic reasons which are described in the Methodology chapter (see 3.3)

## 4.1 Participants

Parents are the ones who answered the questionnaire, but the background questions were both about parents and their children.

### 4.1.1 Parents

In total, 15 parents took part in the study. In the Methodology chapter the process of recruiting the parents for the study has been described (see 3.3). Regarding *ethnicity*, nine Norwegian parents and six ethnic minority parents answered the questionnaire.

**Table 4. 1 Country of origin of parents**

		Frequency	Valid percent
Valid	Norway	9	60,0
	Sri Lanka	3	20,0
	Ghana	1	6,7
	Russia	1	6,7
	Pakistan	1	6,7
	Total	15	100,0

Ethnic minority parents represented four countries: Sri-Lanka (three parents), Ghana, Russia and Pakistan.

Concerning *gender*, five fathers and eight mothers answered the questionnaire. The other two questionnaires were answered by both parents. The questionnaire did not have an option for both parents answering, so they just wrote two answers for all the background variables regarding parents (see Table 2 in Appendix 9). This means that all together 17 parents answered the questionnaire. They are counted as 15 parents in this study, as I just got 15 filled out questionnaires.

The *age* of the parents varied from 35 to 55 years old (seven parents aged bellow 40 and eight parents aged 40 and up), (see Table 3 in Appendix 9).

Regarding *education*, one of the parents had secondary school as the highest level of complete education, seven of the parents graduated from high school and seven from university (see Table 4 in Appendix 9).

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Concerning *child's place of living and family situation*, in six of the represented families children lived with both parents, in three the child with autism spectrum disorder lived with the mother; in one with the father, and three of the families had their children living at an institution. One of the parents answered that the child did not live with both of the parents, but no more specific information was given (see Table 5 in Appendix 9).

The *total number of children* in the families was represented according to the following pattern: one family with four children, four families with three children, five families with two children and five families where the child with autism spectrum disorder is the only one (see Table 6 in Appendix 9).

There were three families in the sample with *more than one child with special needs* and 12 families where the child with autism spectrum disorder was the only child with special needs. All three of the families with more than one child with special needs had ethnic minority background. It would mean that those families would have to cooperate closely with different professionals even more. One of the families has two children with autism spectrum disorder, in the other family the autism spectrum diagnosis was not given, but suspected and in the third family the other child with special needs had low vision (see Table 7 in Appendix 9).

#### **4.1.2 Child with autism spectrum disorder**

Concerning the gender of the child, 11 of the children were boys and four were girls (see Table 8 in Appendix 9)

Children's age varied from nine to 18 (see Table 10 in Appendix 9).

The children were given their diagnoses from four to 15 years ago. This indicates that their parents would have a great variety of number of years of cooperating with professionals, but none of them would have less than four, which would mean they had at least some experience which they could share.

Concerning medical problems in addition to the diagnoses, five of the children had different medical problems (allergy, epilepsy, depression, lactose intolerance, anorexia) and 10 did not (see Table 11 in Appendix 9). This information may also add on cooperation with a wider variety of professionals.

When it comes to the individual plan, 14 of the children had it and only one did not (see Table 12 in Appendix 9).

## 4.2 Cooperation with different professionals

*Research question 1: What are the wishes and experiences of the parents who have a child with autism spectrum disorder in the sphere of cooperation with different professionals? Are there any differences between the wishes and experiences of ethnic minority parents and ethnic Norwegian ones?*

In the questionnaire, cooperation with professionals was covered by 35 items (No. 13-47).

Information concerning the 15 parents' views on cooperation with and support from the professionals that worked with their child and with the families is presented below. The presentation includes information about results from the complete group of parents and their cooperation with and support from professionals as well as parents' answers compared to information given by the respondents about their ethnic background, gender, age, education, number of the children in the family, other children with special needs, medical problems in addition to the diagnosis of the child and years after the diagnosis.

The answers are viewed from the perspective of parents' *wishes or needs* concerning cooperation with professionals as well as what they *experiences* in real life.

Cooperation is the main theme, composed of three sub-themes: *professional support* (4.2.1), *parental involvement in the process* (4.2.2) and the *emotional support* given by professionals to parents (4.2.3)



### 4.2.1 Professional support

The sub- theme of professional support is covered by items 13 to 35 in the questionnaire. In the analysis below professional support includes nine sub- sub- themes or topics, which are: a) *professional help*; b) *information about educational and therapeutic progress*; c) *continuity of educational and therapeutic services*; d) *professional understanding of child and family's needs*; e) *information about the community services*; f) *weekend and after school activities*; g) *need for honest answers*; h) *parents' assessment of the cooperation*; and i) *additional comments about professional support*.

For some of the items about the wishes I decided to have follow-up questions, asking not only about the parents' wishes but also about how they experienced their wishes being met in real life. Regarding the answers presented in this chapter, some of them are described in detail from both the wish and experience perspectives and some are highlighted only from one perspective. In the end of this subchapter, the answers concerning *parents' assessment of cooperation with different professionals* are described as well as *parents' additional comments* given in an open-ended question.

#### (a) Professional help (items 13 and 14).

##### Parents' need for professional help:

Parents were initially asked if they needed a professional to turn to if their child needed help.

**Table 4. 2 Parents need for professional help**

Answering alternatives	Frequency	Valid Percent
Valid    very important	12	80,0
rather important	3	20,0
Total	15	100,0

N=15, n=15

This table shows that the majority of the parents (12:80%) responded “very important” to the given item and a minority of three (20%) viewed the issue as

“rather important”. The item had two additional answering possibilities: “rather unimportant” and “very unimportant”, which were not chosen by the parents. This may indicate that they all considered their need for having a professional to turn to if their child needed help as an important one.

Parents’ *ethnicity* (Item 1, described in 4.1.1) attains additional information, when compared with the answers in table 4.2. As mentioned under the description of the participants, parents’ country of origin represented Norway and four other different countries: Russia, Sri-Lanka, Ghana and Pakistan. In order to do the statistical analysis, Russia, Sri-Lanka, Ghana and Pakistan were put together into one group: called ethnic minority. Table 4.3 shows this comparison.

**Table 4. 3 The need for professional help compared to parents' ethnicity**

			13.If my child needs help I need to have a professional to turn to		
			very important	rather important	Total
Ethnicity	Norwegians	Count	9	0	9
		% Norwegians	100,0%	,0%	100,0%
	ethnic minority	Count	3	3	6
		% ethnic minorities	50,0%	50,0%	100,0%
Total	Count		12	3	15
	% Ethnicity		80,0%	20,0%	100,0%

N=15, n=15, Pearsons Chi-Square ,018

The table illustrates that all Norwegian parents answered “very important” to the question (9:100%), while three of the six parents (50%) with the ethnic minority background answered “very important” and the other three (50%) answered “rather important”. Anyhow all the parents showed that the need for professional help was considered to be important, whereas the degree of importance about the need differed significantly between Norwegians and ethnic minorities (Pearsons Chi-Square ,018)

#### Parents’ access to professional help:

Parents were asked about their experience in having a professional they could contact when their child needed help. The experiences of the parents differed, as shown in

table 4.4.

**Table 4. 4 Parents' access to professional help**

Answering alternatives	Frequency	Valid Percent
Valid yes	9	60,0
partially	5	33,3
no	1	6,7
Total	15	100,0

N=15, n=15

The majority of the parents (9:60%) had a professional they could contact, while the rest answered “partially” (5: 33,3%) or “no” (1: 6,7%).

Additional information appeared also when different background variables were considered.

- *Ethnicity* (Item 1):

**Table 4. 5 Access to professional help compared to parents' ethnicity**

			14.I do have a professional to turn to if my child needs help			Total
			yes	partially	no	
Ethnicity	Norwegians	Count	8	0	1	9
		% Norwegians	88,9%	,0%	11,1%	100,0%
	ethnic minority	Count	1	5	0	6
		% Ethnic minority	16,7%	83,3%	,0%	100,0%
Total		Count	9	5	1	15
		% Ethnicity	60,0%	33,3%	6,7%	100,0%

N15, n=15, Pearsons Chi- Square ,004

Eight of the nine of ethnic Norwegian parents answered “yes” to the question (88,9%) and one answered “no”(11,1%). Ethnic minority parents replied differently. While one answered “yes” (16,7%), five of them (83,3%) answered “partially”. The statistical analysis indicates that there is a significant difference between the answers of ethnic Norwegian and ethnic minority parents about their access to professional help. (Pearsons Chi-Square ,004). In spite of this difference 14 of the 15 parents reported that they did have access to professional help.

*Comments:* None of the ethnic minority parents answered “no” to the item about professional help, which may indicate that all of them had access to it.

- *Education (Item 4):*

All the answers from parents about their highest level of complete education were grouped in two categories: high school and university /college (there is one parent who answered secondary education and this answer is counted in the same group with high school).

**Table 4. 6 Access to professional help compared to parents' education**

			14.I do have a professional to turn to if my child needs help			Total
			yes	partially	no	
education	1	Count	3	5	0	8
		% high school	37,5%	62,5%	,0%	100,0%
	2	Count	6	0	1	7
		% university / college	85,7%	,0%	14,3%	100,0%
Total		Count	9	5	1	15
		% education	60,0%	33,3%	6,7%	100,0%

N=15, n=15, Pearsons Chi-Square ,031

Among the eight parents with high school as the highest level of complete education three of them (37,5 %) answered “yes” to the question about having a professional to turn to , and five (62,5%) answered “partially”. Among the seven parents with university/ college education, six (85,7%) answered “yes” and one parent (14,3%) answered “no”. Statistical analysis indicates that there is a significant difference between the answers of the parents with high school education and the parents with college / university (Pearsons Chi-Square ,031) concerning the degree of access to professional help.

*Comments:* Parents with higher education may have more access to professional help due to the fact that they know both how and where to search or apply for it.

- *Other children with special needs (Item 7).* Item 7 aimed at finding out if there were other children with special needs in the families, or if the child with autism spectrum disorder would be the only one.

**Table 4. 7 Experience of access to professional help compared to other children with special needs**

			14.I do have a professional to turn to if my child needs help			Total
			yes	partially	no	
other children in the family with special needs	yes	Count	0	4	0	4
		other children in the family with special needs	,0%	100,0%	,0%	100,0%
	no	Count	9	1	1	11
		other children in the family with special needs	81,8%	9,1%	9,1%	100,0%
Total		Count	9	5	1	15
		other children in the family with special needs	60,0%	33,3%	6,7%	100,0%

N=15, n=15, Pearsons Chi-Square ,004

The table shows that a majority of the parents (11) only had one child with special needs, while four of the parents did have two or more children with special needs. Among the 11 parents with one child with special needs, nine parents (81,8%) answered “yes”, one (9,1%) answered “partially” and one (9,1%) answered “no”. On the other hand, among the families with two or more children with special needs, all the four parents answered “partially” to the item. Statistical analysis indicates that there is a significant difference between the answers of parents of one child with special needs and parents of multiple special needs children about their access to professional help. (Pearsons Chi-Square ,004)

- *Number of number of years after diagnosis (Item 10):*

The answers to the item were grouped in two categories: the first group was when the child received the diagnosis less than 10 years ago; and the second one, when the child was diagnosed 10 and more years ago.

**Table 4. 8 Experience with having access to the professional help compared to the number of number of years after diagnosis**

	14.I do have a professional to turn to if my child needs help	Total
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		yes	partially	no	
Years after diagnoses	Count	3	5	0	8
	% less than 10 years	37,5%	62,5%	,0%	100,0%
	Count	6	0	1	7
	% more than 10 years	85,7%	,0%	14,3%	100,0%
Total	Count	9	5	1	15
	% years after diagnoses	60,0%	33,3%	6,7%	100,0%

N=15, n=15, Pearsons Chi-Square ,031

Three of the eight parents whose child had been given a diagnosis less than ten years ago answered “yes” to the question about professional help (37,5%) and five answered “partially” (62,5 %). The parents with the child who had been given the diagnosis more than ten years ago responded differently to this item: six of them (85,7%) answered “yes” and one (14,3%) answered “no”. Statistical analysis indicates that there is a significant difference between the answers of parents with a child diagnosed less than 10 years ago and parents with a child diagnosed more than 10 years ago, regarding their access to professional help. (Pearsons Chi-Square ,031).

*Comments:* It may indicate that professional help gets better over time, according to the experiences of this particular group of parents. It may also indicate that professionals and parents get to know each other better over a longer period of time.

Summary on the topic of professional help: All the 15 parents considered the need for professional help as important. A comparison of the answers with background information revealed a certain difference between the parents’ answers related to ethnicity, education, number of children with special needs in the family and number of number of years after diagnosis.

**(b) Information about educational and therapeutic progress (Item 15)**

Parents’ wishes concerning information:

There were four possibilities of answering to the statement: “very important”, “rather important”, “rather unimportant” and “very unimportant”.

**Table 4. 9 Parents' wish for information about child's educational and therapeutic progress**

	Frequency	Valid Percent
Valid    very important	15	100,0

N=15, n=15

All the 15 parents (100%) chose “very important” as an answer to the item “Information about my child’s educational or therapeutic progress should be given to me”.

*Comments:* It is interesting to see that all parents had the opinion that information about the educational and therapeutic progress was of high importance. This was the case also when background variables were considered. Information is a field where professionals have a main task in cooperating activities.

**(c) Continuity of educational and therapeutic services (Item 20).**

Parents' wishes concerning services:

As was the case concerning information, all the 15 parents answered “very important” to the statement “Educational and therapeutic services appropriate for my child should be continuous”. This means that parents agreed on the high importance of the continuity of the services given to their child.

**Table 4. 10 Parents' wishes for educational and therapeutic services being continuous**

	Frequency	Valid Percent
Valid    very important	15	100,0

N=15, n=15

*Comments:* This is also an item where the nature of cooperation is mainly driven by professionals.

**(d) Professional understanding of child and family's needs** (Items 21 and 22).

Parents' wish concerning professionals' understanding:

The 15 parents all agreed about the importance of professionals understanding the needs of both the child and the family, and considered this “very important”.

*Table 4. 11 Parents wishes concerning understanding they get from professionals*

	Frequency	Valid Percent
Valid very important	15	100,0

N=15, n=15

*Comments:* This is also the case where all the 15 parents agreed in spite of their background information. Making professionals understand both the needs of the child and the needs of the family are of highest importance for the parents, and a key point in making cooperation working both ways.

Parents' experiences concerning professionals' understanding:

Parents' answers about their experiences in having professionals who understood both the needs of the child as well as the needs of their families showed a variety, though the absence of negative experience (0 parents answered “no” to this item) may be observed.

*Table 4. 12 Parents' experiences concerning understanding they get from professionals*

Answering alternatives	Frequency	Valid Percent
Valid Yes	9	60,0
partially	6	40,0
Total	15	100,0

N=15, n=15

Nine of the 15 parents (60%) experienced that the professionals they cooperated with understood both the needs of their child as well as the needs of their families; and six (40%) replied “partially”.

*Comments:* It is important that parents feel that professionals understand the needs of their children as well as the needs of their families. Even though all parents answered



some degree of understanding, it is interesting to notice that as many as 6 out of 15 only answered it “partially”.

- Additional information is attained if the answers are compared to *the total number of children* in the family (Item 6). Answers of the parents in the category “number of children in the family” were grouped in two subcategories: families with one child and families with more than one child, in order to be able to analyse the difference in the answers (if any) of the parents in the families where the child with autism spectrum disorder is the only child and the parents of families where children have siblings.

**Table 4. 13 Parents experiences with professional understanding compared to total number of children in the family**

			22.The professionals I cooperate with do understand the needs of my child as well as the needs of my family		
			yes	partially	Total
numberofchildren	1	Count	5	0	5
		% one child	100,0%	,0%	100,0%
	2	Count	4	6	10
		% more than one	40,0%	60,0%	100,0%
Total		Count	9	6	15
		% within numberofchildren	60,0%	40,0%	100,0%

N=15, n=15, Pearsons Chi-Square ,025

Among the 15 parents, five had only one child. All of those five parents (100 %) from the families with one child answered that the professionals understood their needs as well as the needs of their families. While among the ten families with more than one child, four of the parents (40%) answered “yes” and six parents (60%) answered “partially” to the question. Statistical analysis indicates that there is a significant difference between the answers of parents of one child and parents with multiple children about professional understanding. (Pearsons Chi-Square ,025).

*Comments:* Having one child in the family may make the number of professionals

parents cooperate with lower than for the families with multiple children, but none of the families experienced professionals not understanding their needs at all.

Summary on the topic of professional understanding of child and family's needs: All the 15 parents wished for professional understanding of their needs. Their experience with professional understanding differed. Additional information was gained when the experience of the parents was compared to the total number of the children in the family.

**(e) Information about the community services (Item 24).**

Parents' experiences concerning getting the information about the community services:

Table 4.14 shows the parents' answers concerning the experiences as to whether they got information about community services or not.

*Table 4. 14 Parents' experience with the information about community services they get*

Answering alternatives	Frequency	Valid Percent
Valid yes	4	26,7
partially	6	40,0
no	5	33,3
Total	15	100,0

N=15, n=15

The parents' answers were almost equally distributed between the three alternatives, as four of the parents (26, 7%) chose "yes", six (40%) chose "partially" and five (33, 3%) - "no". One of the parents wrote in addition: "BAD!! We need to find out everything ourselves".

*Comments:* It is interesting to see the distribution on this item. Answers to this particular item may indicate how different parents experience the accessibility of the information about the community services.

One of the background variables, *education* (Item 4), seems to be related to the

answers about information on community services.

**Table 4. 15 Experience with getting complete information about community services compared to parents' education**

		24.I do get the complete information about the services of the community appropriate for my child			
		yes	partially	no	Total
education	Count	1	2	5	8
	% high school	12,5%	25,0%	62,5%	100,0%
	Count	3	4	0	7
	% college/university	42,9%	57,1%	,0%	100,0%
Total	Count	4	6	5	15
	% within education	26,7%	40,0%	33,3%	100,0%

N=15, n=15, Pearsons Chi-Square ,036

As we have seen before (4.2.1 (a)), eight of the 15 parents had high school as their highest level of complete education, while seven parents had college/university education. Among the first group one (12,5%) answered “yes”, two (25%) replied “partially” and five parents (62,5%) answered “no” as to whether they got complete information about community services. Among the parents with university education, three (42,9%) replied “yes”, while four (57,1%) answered “partially”. Statistical analysis indicates that there is a significant difference between the answers of parents with high school education and parents with university/college education (Pearsons Chi-Square ,036) about the information about the community services.

*Comments:* The results may indicate that parents with higher education may have more access to the information due to the fact that they know how and where to find it.

**(f) Weekend and after school activities (Item 28 and 29):**

Parents' wishes concerning weekend and after school activities being provided by the professionals:

Parents were asked whether it was important for them that professionals were the ones who provided weekend and after school activities for their children. Their answers are shown in table 4.16.

**Table 4. 16 Parents' wishes for weekend and after school activities being provided by professionals**

		Frequency	Valid Percent
Valid	very important	8	57,1
	rather important	5	35,7
	rather unimportant	1	7,1
	Total	14	100,0
Missing	missing out	1	
Total		15	

N=15, n=14

The replies show that a majority of the parents (8:57,1%) considered professional provision of weekend and after school activities as “very important”, five (35,7%) as “rather important” and one (7,1) as “rather unimportant”.

Parents' experiences concerning weekend and after school activities being provided by the professionals:

Item 29 aimed at finding out whether the parents really had weekend and after school activities provided by professionals. The results are shown in table 4.17.

**Table 4. 17 Parents' experience as to whether weekend and after school activities were provided by professionals**

Answering alternatives		Frequency	Valid Percent
Valid	yes	2	14,3
	partially	6	42,9
	no	6	42,9
	Total	14	100,0
Missing	missing out	1	
Total		15	

N=15, n=14

Of the 14 parents who answered this question the majority answered that weekend and after school activities were provided by professionals: “yes” (2) and “partially” (6), but six of the 14 parents (42,9 %) answered “no” to this question, meaning that they did not get any activities provided by professionals at all. Some of the parents who answered “partially” or “no” wrote additional comments. Those comments were: “my child needs more activities in the institution” and “my application has been denied”.

*Comments:* Weekend and after school activities are an important part of the schedule of any child. Having a child with special needs may make the parents need help from professionals in providing the child with such activities. As we saw in table 4.16 the importance of the wish was quite high, but parents experienced it differently in real life

The answers in table 4.17 were compared with the background variable *the total number of children in the family* (Item 6). The results are shown in table 4.18.

**Table 4. 18 Parents' experience with weekend and after school activities compared to total number of children in the family**

			29. My child is provided with weekend and after school activities by professionals			Total
			yes	partially	no	
Number of children	1	Count	0	0	5	5
		% one child	,0%	,0%	100,0%	100,0%
	2	Count	2	6	1	9
		% more than one child	22,2%	66,7%	11,1%	100,0%
Total		Count	2	6	6	14
		% within number of children	14,3%	42,9%	42,9%	100,0%

N=15, n=14, Pearson Chi-Square ,006

All the five parents (100 %) from the families with one child answered that the weekend and after school activities were not provided by professionals. While among the nine families with more than one child, two of the parents (22,2%) answered “yes”, six parents (66,7%) answered “partially” and one (11,1 %) answered no. Statistical analysis indicates that there is a significant difference between the answers of parents of one child and parents of multiple children (Pearsons Chi-Square ,006) about the information about the weekend and after school activities.

Another background variable, *medical problems* (Item 11), also seems to be related to the answers about parents' experiences concerning weekend and after school activities.

**Table 4. 19 Parents' experience with weekend and after school activities compared to medical problems the child has/has not in addition to the diagnosis**

			29. My child is provided with weekend and after school activities by professionals			Total
			yes	partially	no	
11. Medical problems in addition to the diagnosis	yes	Count % the child has medical problems	2 50,0%	0 ,0%	2 50,0%	4 100,0%
	no	Count % the child doesn't have medical problems	0 ,0%	6 60,0%	4 40,0%	10 100,0%
Total			2 14,3%	6 42,9%	6 42,9%	14 100,0%

N=15, n=14, Pearsons Chi-Square ,024

Among the four parents whose child had medical problems in addition to the diagnosis, two of them (50%) answered “yes” to the question about professional provision of weekend and after school activities and 2 (50%) answered “no”. Among the ten parents whose child did not have medical problems, six (60%) answered “partially” and 4 (40%) answered “no”. Statistical analysis indicates that there is a significant difference between the answers of parents whose child did not have medical problems and whose child did (Pearsons Chi-Square ,024) concerning the provision of activities.

Summary on “Weekend and after school activities”: the majority of the parents (13) wished for a professional provision of activities. They had different experiences with the activities being provided by professionals. Additional information was gained when the experience of the parents was compared to the total number of children in the family and medical problems in addition to the diagnosis.

**(g) Need for honest answers (Item 30).**

Parents' wish concerning professionals' answers to their questions:

As it was the case with Items 15, 20 and 21, all the 15 parents answered “very

important” to the statement “I need honest answers to my questions from the professionals”.

**Table 4. 20 Parents' wish for honest answers from professionals**

	Frequency	Valid Percent
Valid    very important	15	100,0

N=15, n=15

*Comments:* This item is also a key item for cooperation; parents wish to know that they have honesty in their relationship with professionals. They may want to hear the truth both about current situations and about prognosis.

**(h) Parents' assessment of the cooperation (Items 31-34).**

The items 31-34 were the items aimed at revealing parents' assessment of the cooperation with different professionals. Most of the parents had contacted the professionals and gotten help. 12(80%) of the parents had positive experience with teachers, 12 of the parents(80%) had the same experience with medical doctors and 13 of them (86,7%) with the assistant personnel (see Tables 31-34 in Appendix 9).

Parents' assessment of cooperation with *psychologists* showed a more varied picture and is presented below.

**Table 4. 21 Parents' assessment of the cooperation with psychologists**

Answering alternatives	Frequency	Valid percent
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Valid	I never contacted these professionals	6	40,0
	I contacted these professionals and did not get help	1	6,7
	I contacted these professionals and got help	6	40,0
	I contact these professionals every time I need help from them	2	13,3
	Total	15	100,0

N=15, n=15

As shown in the table above, six of the parents (40%) never contacted psychologists, one contacted them and did not get help (6,7%), six of the parents (40%) contacted them and got help and two (13,3%) of them took contact with psychologists every time they needed help. The results are also supported by parent's comment: "Neither parents nor a child got any offer; something I asked for several times after the diagnosis had been given".

*Comments:* Psychologists are not among the professionals parents usually cooperate with. Some of the parents commented on it in additional comments.

**(i) Parents' additional comments about professional support:**

Parents were asked to write additional comments about professional support. In Chapter 1.2 the concept of challenge was defined as including both difficult and motivating experiences of parents, which gives reasoning for subdividing the comments into motivating factors and difficulties.

Regarding *motivating factors* two of the parents mentioned that cooperation with professionals was functioning. One of them added that the communication went both ways and parents and professionals had contact with each other when needed.

On the other hand, *the difficulties* mentioned were time ("it takes long time to get an appointment and information about parents' rights" and "long time for cooperation among the professionals themselves to start working"). Other difficulties were concerning access. One of the parents wrote that they had to call the professionals



several times before they could get an appointment. Another difficulty mentioned was that parents often had to be the coordinators between different professionals. Some of the parents had problems with finding “relief-persons” (avlastnings hjelp) and had an opinion that it should be done by the district authorities and not by the parents themselves. One of the mothers highlighted the fact that right after her child got a diagnosis she needed a meeting with a psychologist which she did not get. She thought it should come automatically after such a diagnosis. Finally another parent wrote that some of the professionals were difficult to cooperate with.

Summing up about the professional support Nine topics were identified within the sub-theme professional support (4.2.1). Those nine topics were: professional help, information about educational and therapeutic progress, continuity of educational and therapeutic services, professional understanding of child and family’s needs, information about community services, weekend and after school activities, need for honest answers, parents’ assessment of cooperation and parents’ additional comments about the professional support. All the 15 parents agreed on importance of professional help, information about educational and therapeutic progress, continuity of educational and therapeutic services, professional understanding of the child and family’s needs, and need for honest answers. For some of the topics, statistical analysis identified differences related to ethnicity, education, other children with special needs, number of years after diagnosis, total number of children in the family and medical problems. The analysis of the answers from the open-ended questions revealed that parents experience some difficulties in the cooperation regarding time and access.

#### **4.2.2 Parental involvement in the cooperation process**

The sub-theme of parental involvement was covered by four items in the questionnaire, items 36-39. Item 40 was an open-question aiming at getting additional comments from the parents about their own involvement. Those four items focused on a) parental *involvement in the setting up of Individual Education Plan* and b)

*consideration of parents' opinions in planning of the activities for their child.*

**a) Parents experience with involvement in the setting up of Individual Education Plan (Item 37).**

Parents were asked about their own involvement in the process of setting up Individual Education Plan. The answers are shown in the table 4.22.

**Table 4. 22 Parental involvement in the setting up of Individual Education Plan**

	Frequency	Valid Percent
Valid yes	11	73,3
partially	3	20,0
no	1	6,7
Total	15	100,0

N=15, n=15

Here a clear majority of the parents(11:73,3%) considered themselves being involved in the process of making Individual Education Plan, three of the parents (20%) considered themselves being “partially” involved and one (6,7%) as not involved at all. These results are supported by a comment written by one of the parents: “I have been active enough in it during many years”.

Concerning the involvement, the answers showed a certain difference in comparison to *ethnicity* and *other children with special needs in the family*.

- *Ethnicity* (Item 1):

**Table 4. 23 Parents' involvement in the setting up of Individual Education Plan compared to parents' ethnicity**

			37.I am actively involved in the setting up of Individual Education Plan			Total
			yes	partially	no	
Ethnicity	norwegians	Count	9	0	0	9
		% norwegians	100,0%	,0%	,0%	100,0%
	ethnic minority	Count	2	3	1	6
		% ethnic minority	33,3%	50,0%	16,7%	100,0%
Total	Count		11	3	1	15
	% ethnicity		73,3%	20,0%	6,7%	100,0%

N=15, n=15, Pearsons Chi-Square ,017

All the Norwegian parents (9:100%) replied that they were involved in the process of making their child's Individual Education Plan, while only two of the parents(33,3%) with ethnic minority background viewed themselves as being involved, three of them (50%) considered themselves as being "partially" involved and one (16,7%) as not involved at all. The statistical analysis indicates that there is a significant difference between the answers of ethnic Norwegian parents and ethnic minority ones (Pearsons Chi-Square ,017) concerning involvement in the setting up of Individual Education Plan..

- *Other children with special needs in the family* (Item 7):

**Table 4. 24 Parents' involvement in the setting up of Individual Education Plan compared to the number of special needs children in the family**

			37.I am actively involved in the setting up of Individual Education Plan			Total
			yes	partially	no	
other children in the family with special needs	yes	Count	1	2	1	4
		% other children in the family with special needs	25,0%	50,0%	25,0%	100,0%
	no	Count	10	1	0	11
		% other children in the family with special needs	90,9%	9,1%	,0%	100,0%
Total		Count	11	3	1	15
		% other children in the family with special needs	73,3%	20,0%	6,7%	100,0%

N=15, n=15, Pearson Chi-Square ,031

All families of one child with special needs (11) reported that they were involved in the setting up of Individual Education Plan ("yes":10:90,9%, "partially":1:9,1%). On the other hand, in the families with more than one child with special needs, different experiences are revealed from the parents: one (25%) answered "yes" to the involvement, two (50%) answered "partially" and one (25%) "no". Statistical analysis indicates that there is a significant difference between the answers of parents of one child with special needs and parents of multiple special needs children about

their involvement in the setting up of Individual Education Plan (Pearsons Chi-Square ,031) .

Comments: even if there are only four parents of more than one child represented in the group, their answers may indicate that the degree of involvement in the setting up of Individual Educational Plan decreases with a higher number of the children.

**b) Consideration by the professionals (Item 38).**

Parents were asked if they wish their opinions to be taken into consideration by professionals.

**Table 4. 25 Parents' wish for consideration from professionals**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	12	80,0	80,0	80,0
	rather important	3	20,0	20,0	100,0
	Total	15	100,0	100,0	

N=15, n=15

The table shows that the majority of the parents (12:80%) responded “very important” to the item and a minority of three (20%) viewed the item as “rather important”. The item had two additional answering possibilities: “rather unimportant” and “very unimportant”, which were not chosen by the parents. This may indicate that they all considered their wish for their opinions being considered by professionals as an important one.

- Parents' *ethnicity* (Item 1) attains additional information.

**Table 4. 26 Parents' wish for their opinion to be taken into consideration in comparison with ethnicity**

			38.I want to know if my opinions about the planning of my child's treatments and therapies are taken into consideration by the professionals		
			very important	rather important	Total
Norway or other countries	norwegians	Count	9	0	9
		% within Norway or other countries	100,0%	,0%	100,0%

Total	ethnic minority	Count	3	3	6
		% within Norway or other countries	50,0%	50,0%	100,0%
		Count	12	3	15
		% within Norway or other countries	80,0%	20,0%	100,0%

N=15, n=15, Pearson Chi-Square ,018

All the Norwegian parents (9:100%) replied that they viewed the wish for professional consideration as "very important", while only three of the parents(50%) with ethnic minority background viewed the item as "very important" and three as "rather important". The statistical analysis indicates that there is a significant difference between the answers of ethnic Norwegian parents and ethnic minority ones (Pearsons Chi-Square ,018) concerning the importance of their opinions to be taken into consideration by professionals.

*Comments:* All of the 15 parents considered the item as important, but a degree of importance varied compared to their ethnicity.

### c) **Parents additional comments about parental involvement in cooperation:**

Additional comments of the parents are categorised according to the same principle as described in 4.2.1 (i). The *motivating factor* mentioned by one of the parents, was parent's involvement in the process of cooperation with the professionals for many years. The *difficulties* mentioned were: long time to get involved and the wish for having a professional to follow a child to the activities (a relief person). Change in the personnel group, which made it difficult to conduct activities in the right way was also given as a difficulty in this category.

Summing up about the parental involvement in cooperation. Two topics were identified within the sub-theme parental involvement in cooperation (4.2.2): parents' involvement in the setting up of Individual Education Plan and professional consideration. For some of the topics statistical analysis identified differences related to ethnicity and number of children with special needs in the family. The analysis of the answers from open-ended questions showed that some of the parents had been actively involved in cooperation process and some had difficulties with time it took to

get involved as well as difficulties with changes in professional group.

### 4.2.3 Emotional support given by professionals

Emotional support given by professionals is represented in three topics: *Approval of the decisions parents make concerning their child*, *Helping in remaining positive about child's future*, and *Sharing of hopes and fears*. Answers to only one of those topics revealed additional information in comparison with background information and is presented below.

#### a) **Sharing of hopes and fears** (Item 45).

Getting professionals to share the fears and hopes together with the parents turned out to be an important wish. Parents' answers are presented in table 4.27.

**Table 4. 27 Importance of sharing hopes and fears with professionals**

		Frequency	Valid Percent
Valid	very important	12	80,0
	rather important	3	20,0
	Total	15	100,0

N=15, n=15

All the parents answered that it was important to share hopes and fears with professionals ("very important": 12:80%, "rather important": 3:20%) No negative responses such as "rather unimportant" or "very unimportant" were given to this item.

Concerning the sharing of hopes and fears, the answers showed a certain difference in comparison to *the highest level of complete education* (Item 4)

**Table 4. 28 Parents wish for professionals to share their hopes and fears in comparison with parents' education**

		45.I need professionals for sharing my hopes and fears concerning my child		
		very important	rather important	Total
education	Count	8	0	8

Total	% high school	100,0%	,0%	100,0%
	Count	4	3	7
	% college/university	57,1%	42,9%	100,0%
	Count	12	3	15
	% within education	80,0%	20,0%	100,0%

N=15, n=15, Pearsons Chi-Square ,038

All of the eight parents (100%) with high school as their highest level of complete education viewed the item as "very important", while among the parents with college/university as their highest level of complete education, four (57,1%) answered "very important" and three (42,9%) considered the item to be "rather important".

**b) Additional comments about the emotional support given by the professionals:**

The additional comments from the parents are again categorised according to the same principle as described in 4.2.1(i). As the first *motivating factor* parents admitted that the help given by professionals was important for the needs of the child. As another motivating factor one of the parents mentioned that professional took their time to listen to the parents' problems. The only *difficulty* mentioned here is the fact that the future had not been discussed.

Summing up about the emotional support. For the topic of sharing hopes and fears with professionals, statistical analysis identified differences related to parents' highest level of complete education. The analysis of the answers from open-ended questions revealed that professionals did take time to listen to the parents. The fact that future of a child was not discussed was viewed as the only difficulty.

Summing up about the cooperation with professionals. 14 topics were described and discussed within the theme of professional support under three main sub- themes: professional support, parental involvement in the process of cooperation, and emotional support. Statistical analysis attained additional information about the background variables. Open-ended questions revealed parents opinions on motivating factors and difficulties in the cooperation with different professionals.

### 4.3 Social Contacts

*Research question 2: What are the wishes and experiences of the parents who have a child with autism spectrum disorder in the sphere of social contacts? Are there any differences between the wishes and experiences of ethnic minority parents and ethnic Norwegian ones?*

In the questionnaire, “social contacts” were covered by 16 items (No.48-63). The presentation below includes information concerning the 15 parents’ views on the support and understanding from family members and friends. The information about results from the complete group of parents and their social contacts is presented bellow. Parents’ answers are also compared with information about their ethnic background, medical problems, the number of children with special needs in the family, number of years after diagnosis and medical problems in addition to the diagnosis. The answers of the parents are viewed as in 4.2 from the points of both their wishes (needs) and experiences. There are no sub-themes represented under the theme of professional support, but four topics: a) *parents’ free time outside the family*, b) *networks of parents of children with autism spectrum disorder*, c) *child’s own friends* and d) *child’s activities outside the family* are described. In the end of the sub-chapter parents’ *additional comments* given in an open-ended question are highlighted (e).

#### a) Parents’ free time outside the family (Item 49)

Parents were asked whether they had time to spend outside the family.

**Table 4. 29 Parents' experience with having free time to spend outside the family**

Answering alternatives		Frequency	Valid Percent
Valid	yes	6	40,0
	partially	4	26,7
	no	5	33,3
	Total	15	100,0

N=15, n=15

The parents answers were almost equally distributed between the three alternatives,



as six of the parents (40%) chose “yes”, four (26,7%) chose “partially” and five (33,3%)- “no”. Additional comment was written by one of the parents: “I don’t have enough time to help my children. Can not do anything else”.

*Comments:* The distribution on this item may show different perception of the family (for some parents it may be natural to spend free time with their families) as well as different reality (some parents would probably want to have time to spend outside the family, but can not).

Parents’ *ethnicity* (Item 1) gives additional information, when compared with the answers in table 4.29.

**Table 4. 30 Parents' experience with spending free time outside the family compared to parents' ethnicity**

			49.I do have free time I can spend with my friends outside my family			Total
			yes	partially	no	
Ethnicity	Norwegians	Count	6	2	1	9
		% ethnicity	66,7%	22,2%	11,1%	100,0%
	ethnic minority	Count	0	2	4	6
		% ethnicity	,0%	33,3%	66,7%	100,0%
Total		Count	6	4	5	15
		% ethnicity	40,0%	26,7%	33,3%	100,0%

N=15, n=15, Pearson Chi-Square ,024

Six of nine of ethnic Norwegian parents answered “yes” to the question (66,7%), two answered “partially” (22,2%) and one (11,1%)-“no”. Ethnic minority parents replied differently. While none answered “yes”, two out of six (33,3%) replied “partially” and four (66,7%) answered “no”. The statistical analysis indicates that there is a significant difference between the answers of ethnic Norwegian and ethnic minority parents about their experiences with spending free time outside the family. (Pearsons Chi-Square ,024)

*Comments:* An ethnic minority family may not have such a broad network of friends in Norway as ethnic Norwegians, that is why none of them answered “yes” and the

majority answered “no”. Language and different perception of the family may also be the reason.

- Number of years after diagnosis (Item 10):

**Table 4. 31 Parents' experience with spending free time outside the family compared to number of years after diagnosis**

			49. I do have free time I can spend with my friends outside my family			Total
			yes	partially	no	
Number of years after diagnosis	1	Count	1	2	5	8
		% less than 10 years	12,5%	25,0%	62,5%	100,0%
	2	Count	5	2	0	7
		% more than 10 years	71,4%	28,6%	,0%	100,0%
Total		Count	6	4	5	15
		% number of years after diagnosis	40,0%	26,7%	33,3%	100,0%

N=15, n=15, Pearsons Chi-Square ,022

One out of eight parents(12,5%) whose child had been given a diagnosis less than ten years ago answered “yes” to the question about their free time outside the family, two (25%) answered “partially” and five (62,5%) answered “no”. The parents with a child who had been given the diagnosis more than ten years ago responded differently to this item: five of them (71,4%) answered “yes” and two (28,6%) answered “partially”. The statistical analysis indicates that there is a significant difference between the answers of parents with the child diagnosed less than 10 years ago and parents with the child diagnosed more than 10 years ago about their experience with free time outside the family (Pearsons Chi-Square ,022).

*Comments:* Parents of a child diagnosed more than 10 years ago may have their child partially or 100% living in the institution, which probably allows parents more free time outside the family.

#### **b) Network of parents of children with autism spectrum disorder(Items 53**

and 54)

Parents' wish for network of parents of children with autism spectrum disorder:

Table 4.32 shows the parents' answers concerning the importance of having a network of parents with a child with autism spectrum disorder.

**Table 4. 32 Importance of having a network of parents with a child with autism spectrum disorder**

Answering alternatives		Frequency	Valid Percent
Valid	very important	4	26,7
	rather important	8	53,3
	rather unimportant	2	13,3
	very unimportant	1	6,7
Total		15	100,0

N=15, n=15

The replies show that that a majority of parents consider the item to be important: four parents (26,7%) as "very important" (53,3%), eight parents considered it "rather unimportant". Among the three parents who did not consider the item as an important one, two (13,3%) answered "rather unimportant" and one (6,7%) as "very unimportant".

One of the background variables, *other children with special needs in the family* (Item 7), seems to be related to the answers about the network of parents of children with autism spectrum disorder.

**Table 4. 33 Importance of having a network of parents with a child with autism spectrum disorder compared to other children with special needs in the family**

			53.I need to have a network of parents who have a child with the same disorder				Total
			very important	rather important	rather unimportant	very unimportant	
other children in the family with special needs	yes	Count	0	1	2	1	4
		% other children in the family with special needs	,0%	25,0%	50,0%	25,0%	100,0%
	no	Count	4	7	0	0	11
		% other children in the family with special needs	36,4%	63,6%	,0%	,0%	100,0%
Total		Count	4	8	2	1	15
		% other children in the family with special needs	26,7%	53,3%	13,3%	6,7%	100,0%

N=15, n=15, Pearsons Chi-Square ,015

All the 11 parents of one child with special needs considered the item to be important: four parents (36,4%) answered “very important” and seven (63,6%) answered “rather important”. On the other hand, among the parents of two or more children with special needs only one parent (25%) considered it to be “rather important” while the rest did not give importance to the item: two (50%) answered “rather unimportant” and one (25%) as “very unimportant”. The statistical analysis indicates that there is a significant difference between the answers of parents of one child with special needs and parents of multiple children with special needs about the network of parents with children with autism spectrum disorder. (Pearsons Chi-Square ,015)

*Comments:* it is interesting to see that all of the parents of one child with special needs considered the item to be important, while most of the other group did not. It may indicate that parents with the families with more than one child with special needs wouldn't want to have different networks of parents (if their children have different disorders).

Parents' experiences with having a network of parents of children with autism spectrum disorder:

Parents were asked about their experiences with having a network of parents of children with autism spectrum disorder. Their experiences differed as shown in table 4.34.

**Table 4. 34 Parents experiences with having a network of parents with a child with autism spectrum disorder**

Answering alternatives	Frequency	Valid Percent
Valid yes	3	20,0
partially	6	40,0
no	6	40,0
Total	15	100,0

N=15, n=15

A minority of the parents (3:20%) had a network of parents of children with autism spectrum disorder, while six of the parents (40%) had it partially and six(40%) did not have it at all.

Additional information appeared also when ethnicity (Item 1) was considered:

**Table 4. 35 Parents' experience with having a network of parents of children with autism spectrum disorder**

			54.I do have a network of parents who have a child with the same disorder			Total
			yes	partially	no	
Ethnicity	norwegians	Count	1	6	2	9
		% within Norwegians	11,1%	66,7%	22,2%	100,0%
	ethnic minority	Count	2	0	4	6
		% ethnic minority	33,3%	,0%	66,7%	100,0%
Total		Count	3	6	6	15
		% ethnicity	20,0%	40,0%	40,0%	100,0%

N=15, n=15, Pearsons Chi-Square ,036

One of the nine of ethnic Norwegian parents answered “yes” to the question (11,1%), the majority (6:66,7%) answered “partially” and two (22,2%)- “no”. Ethnic minority parents replied differently. While two answered “yes” (33,3%), four of them (66,7%)

answered “no”. The statistical analysis indicates that there is a significant difference between the answers of ethnic Norwegian and ethnic minority parents about the experiences with network of parents of children with the same disorder. (Pearsons Chi-Square ,036).

**c) Child’s own friends (Items 57 and 58)**

Parents’ wish for their child to have friends:

Table 4.36 shows the parents answers concerning the wishes for their children to have friends.

***Table 4. 36 Parents' wishes for the friends for their child***

Answering alternatives		Frequency	Valid Percent
Valid	very important	5	35,7
	rather important	5	35,7
	rather unimportant	2	14,3
	very unimportant	2	14,3
	Total	14	100,0
Missing	missing out	1	
Total		15	

N=15, n=14

Ten of the parents considered the item as important: five (35,7%) as ”very important” and five(35,7%) as “rather important”. On the other hand four of the parents viewed it as unimportant: two (14, 3%) as “rather unimportant” and two (14,3%) as “very unimportant”. An additional comment was given by one of the parents: “It is difficult with social contacts for a child because of the diagnosis”.

The answers in table 4.36 were compared with the background variable *a total number of the children in the family* (Item 6). The results are shown in table 4.37

**Table 4. 37 Parents' wishes for the friends for their child compared to total number of children in the family**

			57.I want my child to have his/her own friends				Total
			very important	rather important	rather unimportant	very unimportant	
Number of children	1	Count	4	0	0	1	5
		% one child	80,0%	,0%	,0%	20,0%	100,0 %
	2	Count	1	5	2	1	9
		% more than one child	11,1%	55,6%	22,2%	11,1%	100,0 %
Total		Count	5	5	2	2	14
		% number of children	35,7%	35,7%	14,3%	14,3%	100,0 %

N=15, n=14, Pearsons Chi-Square ,040

Four of the five parents (80%) from the families with one child answered that it was “very important” for their child to have friends and one (20%) answered “very unimportant”. While among the nine families with more than one child, all the four answering alternatives were chosen. One of the parents (11,1%) answered “very important”, five parents (55,6%) answered “rather important”, two (22,2%) replied “rather unimportant” and one (11,1 %) – “very unimportant”. The statistical analysis indicates that there is a significant difference between the answers of parents of one child and parents of multiple children (Pearsons Chi-Square ,040) about the importance of their children to have friends.

*Comments:* parents of multiple children gave less importance to this item probably due to the fact that their children can play together, so that the child with special needs would not feel lonely.

#### Parents' experiences with their child having own friends:

Parents' answers about their children's friends show variety. Though the absence of positive answers (none answered “yes” to this item) may be noticed.

**Table 4. 38 Parents' experience with their child having own friends**

Answering alternatives		Frequency	Valid Percent
Valid	partially	5	35,7
	no	9	64,3
	Total	14	100,0
Missing	missing out	1	
Total		15	

N=15, n=14

Nine of the 14 parents (64,3%) experienced that their children did not have friends and five (35,7%) replied “partially”

*Comments:* due to ramifications of autism spectrum disorder such as difficulties in social interaction, children with autism spectrum disorder do not have their own friends.

Additional information is attained if the answers are compared to the medical problems a child may have in addition to the diagnosis (Item 11).

**Table 4. 39 Parents' experiences with a child's own friends compared to child's medical problems**

			58.My child does have his/her own friends		
			partially	no	Total
Medical problems in addition to the given diagnosis	yes	Count	0	5	5
		% the child has medical problems	,0%	100,0%	100,0%
	no	Count	5	4	9
		% the child doesn't have medical problems	55,6%	44,4%	100,0%
Total		Count	5	9	14
		% medical problems in addition to diagnosis	35,7%	64,3%	100,0%

N=15, n=14, Pearsons Chi-Square ,038

All the five parents (100%) whose child had medical problems in addition to the diagnosis wrote that their child did not have friends. Among the nine parents whose child did not have medical problems, five (55,6%) answered “partially” and four (44,4%) answered “no”. The statistical analysis indicates that there is a significant difference between the answers of parents whose child did not have medical



problems and whose child did (Pearsons Chi-Square ,038) concerning friend of their children.

*Comments:* Medical problems may restrict communication of the child even more, which may be one of the reasoning for answering negatively to the item.

#### **d) Child's activities outside the family (Item 60)**

Item 60 aimed at finding out whether the child with autism spectrum disorder had any activities outside the family. The results are shown in table 4.40.

**Table 4. 40 Parents' experience with child's activities outside the family**

Answering alternatives	Frequency	Valid Percent
Valid yes	4	26,7
partially	8	53,3
no	3	20,0
Total	15	100,0

N=15, n=15

Of all the 15 parents the majority answered that their child had activities outside the family: “yes” (4:26,7%) and “partially” (8:53,3%), but three of the 15 parents (20%) answered “no” to this question, meaning that all the activities were provided by the family.

Additional information may be gained while comparing the answers with the *years after the child has been diagnosed*.(Item 10)

**Table 4. 41 Parents' experience with child's activities outside the family compared to number of years after diagnosis**

			60.My child does have activities outside the family			
			yes	partially	no	Total
Years after diagnoses	1	Count	0	6	2	8
		%less than 10 years	,0%	75,0%	25,0%	100,0%
	2	Count	4	2	1	7
		% more than 10 years	57,1%	28,6%	14,3%	100,0%
Total		Count	4	8	3	15

% years after diagnoses	26,7%	53,3%	20,0%	100,0%
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N=15, n=15, Pearsons Chi-Square ,043

Six of the eight parents (75%) whose child had been given a diagnosis less than ten years ago answered “partially” to the question about activities outside the family and two (25%) answered “no”. The parents with the child who had been given the diagnosis more than ten years ago responded differently to this item: four of them (57,1%) answered “yes”, two (28,6%) answered “partially” and one (14,3%) answered “no”. The statistical analysis indicates that there is a significant difference between the answers of parents with the child diagnosed less than ten years ago and parents with the child diagnosed more than ten years ago about the activities outside the family. (Pearsons Chi-Square ,043).

*Comments:* The results may indicate that it takes time to find activities outside the family for a child with autism spectrum disorder.

#### e) **Parents’ additional comments about social contacts**

Parents revealed different *motivating factors* in the sphere of social contacts: having relatives and a big family who can help was one of them. Being a two-parent family and being able to relieve each other was another one.

As having a big family was a positive factor to some of the parents, others had their families far from Norway and considered this to be one of the *difficulties*, because the child was not able to have contact with the relatives often. Another factor was related to the acting-outs, which are typical for some children with autism spectrum disorder. For one family it was difficult to have their child at home without any assistant personnel being present there all the time. Their child was “too big and strong to control”. Another difficulty which also laid in the nature of the diagnosis was establishing contacts for the child. Finally one of the parents pointed to a difficulty with getting babysitters for the child which led to social isolation for the parent.

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Summing up about the social contacts. Four topics were described and discussed within the theme of social contacts: parents' free time outside the family, network of parents of children with autism spectrum disorder, child's own friends and child's activities outside the family. Statistical analysis attained additional information about the ethnicity, number of years after diagnosis, number of children with special needs in the family, total number of the children, and medical problems in addition to the diagnosis. Open-ended questions revealed that having a big family and being a two-parent family were the motivating factors, while the difficulties mentioned were connected mostly to the ramifications of autism spectrum disorder.



## 5. Chapter 5 Summary, discussions and suggestions

This chapter includes a short summary of findings concerning cooperation with professionals and social contacts (5.1), a discussion of findings related to the two research questions (5.2), validity concerns (5.3) and some suggestions for further research (5.4). The validity concerns have been discussed in sub-chapter 3.6.

### 5.1 Summary of findings

#### Cooperation with different professionals

The analysis of questionnaire data showed that 14 topics could be identified in the sphere of parents' cooperation with different professionals, covering three main sub-themes: *professional support*, *parental involvement in the process of cooperation* and *emotional support*. Concerning professional support, all the 15 parents no matter their background, agreed that four areas of cooperation were "very important": information about educational and therapeutic progress, the continuity of educational and therapeutic services, professional understanding of child, and family's needs and need for honest answers. Bivariate statistical analysis identified relationship (Pearsons Chi-Square varying from ,004 till ,038) between some parents cooperation with professionals and some of the background information (e.g. ethnicity, number of children with special needs in the family etc)and background variables (see 4.2).

Open- ended questions revealed that parents experienced some difficulties regarding time and access for professional support. Regarding parental involvement, the group of parents had different experiences: some had been actively involved in cooperation process, and for some it took long time to get involved. Concerning emotional support, the time professionals spent to listen to the parents was experienced as a motivating factor by the parents. On the other hand, the fact that future of the child was not discussed between parents and professionals was experienced as a problem.

### **Social contacts**

In this sub- theme the analysis identified four topics: parents' free time outside the family, social network of parents of children with autism spectrum disorder, the child's own friends and the child's activities outside the family. Bivariate statistical analysis identified relationship (Pearsons Chi-Square varying from ,015 till ,043) between social contacts and some of the background information (e.g. ethnicity, total number of children in the family etc.), (see 4.3). Open-ended questions revealed that in the sphere of social contacts parents considered family contacts to be a motivating factor, while the ramifications of autism spectrum disorder were factors that reduced social interaction for a family.

## **5.2 Discussion**

The research problem of this study is:

*What challenges in the spheres of cooperation with different professionals and social contacts do parents face while raising a child diagnosed with autism spectrum disorder?*

### **5.2.1 Cooperation with professionals**

The first research question deduced from the research problem was: *“What are the wishes and experiences of the parents who have a child with autism spectrum disorder in the sphere of cooperation with different professionals? Are there any differences in wishes and experiences of ethnic minority parents and ethnic Norwegian ones?”*

*Agreement on importance of cooperation:*

All parents agreed on the importance of the following cooperation aspects: need for professional help (see 4.3.1.a); wish for information about educational and therapeutic progress (see 4.2.1.b); wish for the continuity of educational and therapeutic services (see 4.2.1.c); wish for professional understanding of child's and

family's needs (see 4.2.1.d); need for honest answers (see 4.2.1.g); parents wish for consideration from professionals (see 4.2.2.b); and wish for sharing hopes and fears with professionals (4.2.3.a). The agreement on importance of the needs and wishes show that parents of children with autism spectrum disorders have very much in common in spite of any differences on their background, like ethnicity, education, gender, age etc.

*Results compared to previous research:*

The importance of information about services available was described by Beresford (1996), as well as the fact that information helped parents in coping and enables them to demand the appropriate services for the child. In the present study parents replied differently to this item (see 4.2.1.e). It seems that for some of them, the access to information was a motivating factor while for others it created difficulties. The answers also may indicate that parents with higher education had more access to the information about the services (see 4.2.1.e). This may be related to parents' ability to work with information, knowing where and how to search for it.

The importance of honest prognosis (and not unfairly optimistic) was underlined by Gray (1994 and by Beresford 1996). All the 15 parents in my study emphasised that it was very important for them to get honest answers from professionals (see 4.2.1.g). This finding is pointing in the same direction as the previous studies.

Another aspect, which should be highlighted in this discussion, is respect given to the parents' right to make the decision (Hornby 1995). All of the 15 parents considered important that their opinions were taken into consideration by professionals (see 4.2.2.b), but the degree of importance varied regarding parents' ethnicity. It may be interesting for further research to study such aspects.

Also the aspects of emotional support from professionals, such as reassurance, being patient and encouraging, have been emphasized by previous studies (Hornby 1995, Gray 1994). All the parents in my study considered sharing their hopes and fears with professionals to be important (see 4.2.3.b). The finding is pointing in the same

direction with the previous research and may indicate that parents' view cooperation with professionals more broadly than just support on child's progress.

*My expectations regarding the sphere of cooperation:*

The discussion below is related to the expectations presented in Chapter 1.3. Summed up the expectations were:

- Ethnic minority parents might experience more difficulties in cooperation with professionals.
- Mothers might experience more difficulties than fathers do in cooperation with professionals.
- One-parent families might be more dependent on cooperation with professionals than two-parents families do.
- Parents of multiple children with special needs might cooperate more with professionals.

The expectations were based mainly on previous studies, but also on my own experience.

As we saw in Chapter 1.1, the concept of "challenge" refers to both difficulties and motivating factors (Weldeab 2006, Sinclair and Hanks 1997, Olsson 2004). The analysis of the answers (see Chapter 4.2) revealed that parents had both difficulties and motivating factors in cooperation with different professionals.

The fact that parents had an access to professional help was clearly a motivating factor for the majority of parents in their coping with the stress related to parenting a child with autism spectrum disorder. Ethnic minority parents had this access as well, but may be not to the extend they wished, as five out of the six ethnic minority parents answered "partially" to this item. This finding may support the first expectation of the study. What may stop some ethnic minority parents from getting the access was not in the focus of this study, but may be interesting in further



research.

One of the expectations for this study was, as named above, that ethnic minority parents might experience more difficulties in cooperation with professionals than ethnic Norwegians do. There is another finding which supports this expectation. Previous research indicates that active parental involvement should get support from professionals (Swap 1993, cited in Hornby 1995). Though a clear majority of parents in my study considered themselves being involved in setting up of individual education plan, ethnic minority parents considered themselves less involved than Norwegians (see 4.2.2.a). The parents of multiple children with special needs were also less involved than parents of one child (see 4.2.2.a). This may suggest that ethnicity and number of children with special needs should be given special attention in the aspect of parental involvement.

The analysis did not support expectations related to gender of the parents or one-parent families.

Parents with multiple children with special needs reported that they had professionals they could ask for help (see 4.2.1.a), but again not to the extent they wanted. This finding is the opposite of what I expected. It may be connected to the fact that parents of multiple children with disabilities usually have to relate to a high number of professionals. Another finding, pointing in the same direction, was the fact that fewer parents with multiple children with special needs were involved in the setting up of individual education plan than parents of one child with special needs (see 4.2.2.a). This may be related to the fact that setting up of more than one individual education plan in addition to all the other cooperating activities may take a lot of time and efforts from the parents' side.

### **5.2.2 Social contacts**

The second research question deduced from the research problem was: *“What are the wishes and experiences of the parents who have a child with autism spectrum*

*disorder in the sphere of social contacts? Are there any differences in wishes and experiences of ethnic minority parents and ethnic Norwegian ones?"*

As reported in Chapter 2, providing different activities for the family helps a family to be as independent as possible (Gray 1994). The findings of the present study show that some of the parents had difficulties with finding activities for their child with autism spectrum disorder (see 4.3.d). This may have a direct influence on the activities of the whole family due to the fact that the needs of the child with autism spectrum disorder often have to be prioritized.

Another important issue in the sphere of social contacts presented in previous research is support groups of parents who have children with the same disorder. According to Hallahan & Kaufman (1991) those groups are helping families to be independent from traditional professional-parent relations. The findings showed that a majority of ethnic Norwegian parents had access to such groups, whereas most of ethnic minority parents had not (see 4.3.b). The findings could serve as a basis for further research on the topic as well as an idea that parental support groups might have more focus on parents with ethnic minority background.

The importance and effectiveness of social contacts is emphasized by Agosta & Melda (1995). The findings in my study revealed that being a two-parent family may serve as a motivating factor as well as having a big family in general (see 4.3.e)

*Expectations regarding the sphere of social contacts:*

The discussion below is based on the expectations presented in Chapter 1.3 regarding findings in the sphere of social contacts. Summed up the expectations were:

- Minority parents might have less social contacts than ethnic Norwegian parents did.
- Two-parent families might have more social contacts than one-parent families.

As the findings of this study indicate, ethnic minority parents had less contact with the parents of children with the same diagnosis than ethnic Norwegian parents did (see 4.3.b). This may be connected both to unwillingness to participate as well as to

difficulties in getting into such groups. Ethnic minority parents also considered the absence of members of extended family in Norway to be a difficulty (see 4.3.e).

Answers of the parents support the expectation.

The findings of the study did not support on the expectation regarding two- parent families.

### 5.3 Concluding remarks

The study has revealed that the 15 parents of children with autism spectrum disorders did have access to cooperation with professionals within health, educational and psychological services, as well as some social contacts. Challenges they faced included problems related to time it took to get the services, access to professional support and satisfactory social network. On the other hand many parents experienced as a motivating factor the emotional support professionals gave them. Parents with ethnic minority background and with multiple children with special needs seemed to experience less satisfactory cooperation with professionals and also had less acceptable social network.

Based on results of this thesis, I would like to suggest some issues for the future research in the field of parenting a child with autism spectrum disorders.

- There is a shortage of research on challenges for ethnic minority parents of children with autism spectrum disorder. The present study revealed some of the differences between ethnic Norwegian parents and ethnic minority ones. Future research may focus more closely on wishes and experiences of ethnic minority parents.

- The present study has tried to highlight motivating factors as well as difficulties parents face. Difficulties parents had in both cooperation and social contacts dominated, but some motivating factors were also identified. Perhaps such factors may be a main focus for future research in the spheres of cooperation with professionals and social contacts.

- When the cooperation with the professionals is discussed in terms of services the parents get, the findings can reflect both the services not being suitable for the needs of the family and the family not accessing available services from the community.

Researching this question may have helped to understand the nature of the cooperation better.

-In this study the sphere of cooperation with professionals was narrowed down mainly to teachers, medical doctors and psychologists. An idea for future research may be to focus more on authority persons parents have to cooperate with. This idea was given by the parents themselves.

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# Appendices

## Appendix 1. Letter of Introduction from the University of Oslo



**UNIVERSITY  
OF OSLO**

**Department of Special Needs Education**

P.O.Box 1140, Blindern  
N-0318 Oslo  
NORWAY

*Visiting address:*  
Helga Eng's Building  
3rd and 4th floor

Telephone: + 47 22 85 80 59  
Telefax: + 47 22 85 80 21

**FACULTY OF EDUCATION**

Your ref:  
Our ref: int. 45/07  
Contact person: Denese Brittain: [d.a.brittain@isp.uio.no](mailto:d.a.brittain@isp.uio.no)  
Date: September 20. 2007

### To whom it may concern:

This is to confirm that **Nadiya KONOVALOVA**, date of birth 21 April 1982, is enrolled as a full-time student on the international Master of Philosophy in Special Needs Education Programme (M. Phil. SNE) at the Department of Special Needs Education (DSNE), University of Oslo, Norway. Her master's studies commenced on 15<sup>th</sup> August 2006 and are due to be completed on 31<sup>st</sup> May 2008.

DSNE can confirm that the Master of Philosophy in Special Needs Education (M. Phil. SNE) is a two-year full-time study programme involving course work and field work/collection of data and culminating in the writing of a Master's thesis. Nadiya Konovalova is now in her third semester and her plan to conduct research and write her thesis on the following topic: "Challenges in Parenting a Child with Autism Spectrum Disorder for Ethnical Minority Families" has been approved by the department. It is in this connection that she has developed a questionnaire to be used in her field work survey, and together with the follow-up interviews, this material will be used in her research project. Professor Liv Randi Opdal from DSNE has been appointed as the student's Norwegian adviser.

We hope that this provides you with the confirmation that is necessary concerning Nadiya Konovalova's research. If you require any additional information please do not hesitate to contact the Department of Special Needs Education.

Yours sincerely

Denese A Brittain  
Senior Executive Officer  
Administrative coordinator M. Phil. SNE

Institutt for spesialpedagogikk  
Det utdanningsvitenskapelige fakultet  
Universitetet i Oslo  
Norge



## Appendix 2. Letter from Norwegian Social Science Data Services

**Norsk samfunnsvitenskapelig datatjeneste AS**  
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



Harald Hårfagres gate 29  
N-5007 Bergen  
Norway  
Tel: +47-55 58 21 17  
Fax: +47-55 58 96 50  
nsd@nsd.uib.no  
www.nsd.uib.no  
Org.nr. 985 321 884

Liv Randi Opdal  
Institutt for spesialpedagogikk  
Universitetet i Oslo  
Postboks 1140 Blindern  
0318 OSLO

Vår dato: 12.11.2007

Vår ref: 17612 / 2 / KS

Deres dato:

Deres ref:

### TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 02.10.2007. All nødvendig informasjon om prosjektet forelå i sin helhet 08.11.2007. Meldingen gjelder prosjektet:

17612	<i>Utfordringer for familier som har barn med autisme, med fokus på samarbeidet med tjenesteapparatet og på familiens sosiale kontaktnett</i>
Behandlingsansvarlig	Universitetet i Oslo, ved institusjonens øverste leder
Daglig ansvarlig	Liv Randi Opdal
Student	Nadiya Konovalova

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, [http://www.nsd.uib.no/personvern/melding/pvo\\_endringsskjema.cfm](http://www.nsd.uib.no/personvern/melding/pvo_endringsskjema.cfm). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/register/>.

Personvernombudet vil ved prosjektets avslutning, 30.04.2008, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

  
Bjørn Henriksen

  
Katrine Utaaker Segadal

Kontaktperson: Katrine Utaaker Segadal tlf: 55 58 35 42

Vedlegg: Prosjektvurdering

✓ Kopi: Nadiya Konovalova, Rolf E. Stenersens allé 21 HO201, 0858 OSLO

Avdelingskontorer / District Offices:

OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. [nsd@uio.no](mailto:nsd@uio.no)  
TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. [kyrre.svarva@svt.ntnu.no](mailto:kyrre.svarva@svt.ntnu.no)  
TROMSØ: NSD, SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. [nsdmaa@sv.uit.no](mailto:nsdmaa@sv.uit.no)

## Personvernombudet for forskning



### Prosjektvurdering - Kommentar

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17612

I prosjektet vil det bli registrert sensitive personopplysninger om etnisk bakgrunn, jf. personopplysningsloven § 2 nr. 8 a).

Personvernombudet har mottatt reviderte informasjonsskriv og finner disse tilfredsstillende.

Prosjektslutt er angitt til 30.04.2008. Senest ved prosjektslutt vil datamaterialet være anonymisert. Med anonyme opplysninger forstås opplysninger som ikke på noe vis kan identifisere enkeltpersoner i et datamateriale, verken direkte gjennom navn eller personnummer, indirekte gjennom bakgrunnsvariabler eller gjennom navneliste/koblingsnøkkel eller krypteringsformel.

## Appendix 3. Cover Letter

### *Dear Participants:*

My name is Nadiya Konovalova. I'm a master student at the Department of Special Needs Education at the University of Oslo- where now I'm writing my master thesis, which has the title: **“Challenges in parenting a child with Autism Spectrum Disorder, with focus on the family's cooperation with different professionals and on the family's sphere of social contacts.”**

I have been working at a Special SFO base in Oslo for children with autism for one year. My job inspired me in starting this project.

With my master project I want to find out what kind of challenges parents may face in parenting a child with Autism Spectrum Disorder. Additional challenges that ethnic minority families may face in comparison with the ethnic Norwegian families who have a child with Autism Spectrum Disorder will be the main focus in this question. This is the reason why I need both ethnic Norwegian and ethnic minority families for my project. I would also like to find out from the families' personal experience what could be done to make the families' cooperation with different professionals better and what would improve the quality of the families' social contacts.

I hope that my master thesis may lead to a better understanding of everyday challenges families have to face while raising up a child diagnosed with Autism Spectrum Disorder As well as give information about what can be done from the families' perspective. *This is why it is important for me that your opinion is represented in my study.*

I hope that you will answer the questionnaire which contains 64 questions. The questionnaire will be sent to you by post with the prepaid return envelope. You will be able to choose whether you want to use the questionnaire in English or in Norwegian.

It's voluntary to take part in the project and you can stop participating at any stage if you wish. All the information I get will be treated confidentially. The research is approved by Personvernombudet for research at the Norwegian Social Science Data Services (NSD)The list with the names and addresses as well as the answered questionnaires will be kept separately in locked cabinets during the project and will be destroyed when the project is over(in April 2008).I have professional secrecy and all the information I get during my project will be treated according to it.

The supervisor for my master project is Professor Liv Randi Opdal at the Department of Special Needs Education at UiO. She can be contacted by the telephones: 91344265 / 22858122 or by email: [l.r.opdal@isp.uio.no](mailto:l.r.opdal@isp.uio.no)

If you have any questions regarding this project, please take contact with me or my supervisor. I'm available by telephones: 93874176 / 22187501 or by email: [nadiyak@student.uv.uio.no](mailto:nadiyak@student.uv.uio.no)  
I would like to thank you in advance for helping me with this project.

Best regards

Nadiya Konovalova

25.09.2007



---

## Appendix 4. Informed consent given by the parents

### Samtykkeerklæring fra foreldre

Sendes til: Professor Liv Randi Opdal (veileder)  
Postboks 1140 Blindern  
0318 Oslo  
e-mail: [l.r.opdal@isp.uio.no](mailto:l.r.opdal@isp.uio.no)

Vi er villige til å svare på spørreskjema i forbindelse med masterprosjektet  
**”Utfordringer for familier som har barn med autisme, med fokus på  
samarbeidet med tjenesteapparatet og på familiens sosiale kontaktnett”.**

Vi er blitt informert om at deltakelse i prosjektet er frivillig, og at vi kan trekke  
oss når som helst hvis vi ønsker det.

Vi gir tillatelse til at spørreskjema kan sendes til oss.

Navn(en eller begge foreldrene kan undertegne)

Mor:.....

Far:.....

Adresse:.....  
.....

Dato.....Underskrift.....

Vi ønsker å motta spørreskjemaet på engelsk  
norsk (kryss av det som passer)

Andre opplysninger/spørsmål:





---

## Appendix 5. Reminding letter 1.

**”Utfordringer for familier som har barn med autisme, med fokus på samarbeidet med tjenesteapparatet og på familiens sosiale kontaktnett”.**

### *Påminnelse*

*Kjære Foreldre/Foresatte,*

For cirka to uker siden sendte jeg ut en forespørsel om dere var villige å svare på spørreskjema angående **”Utfordringer for familier som har barn med autisme, med fokus på samarbeidet med tjenesteapparatet og på familiens sosiale kontaktnett”**.

Jeg har fått inn en del svar, men håper at enda flere vil delta.

Dette purrebrevet går til alle aktuelle foreldre. Dersom dere allerede har sendt inn samtykkeerklæringen, ber jeg dere om å se bort fra dette brevet.

Vedlagt dette brevet er samtykkeerklæring, som jeg ber dere om å fylle ut og sende til min veileder. Se adressen øverst på samtykkeerklæring eller nederst på dette brevet.

Jeg ber om dere svarer så fort som mulig.

På forhånd takk for hjelpen!

Med vennlig hilsen

Nadiya Konovalova

11.12.2007

Sendes til: Professor Liv Randi Opdal (veileder)  
Postboks 1140 Blindern  
0318 Oslo  
e-mail: [l.r.opdal@isp.uio.no](mailto:l.r.opdal@isp.uio.no)



## Appendix 6. Reminding Letter 2.

**”Utfordringer for familier som har barn med autisme, med fokus på samarbeidet med tjenesteapparatet og på familiens sosiale kontaktnett”.**

Dette purrebrevet går til alle aktuelle foreldre. Dersom dere allerede har sendt inn spørreskjemaet, ber jeg dere om å se bort fra dette brevet.

### *Påminnelse*

*Kjære Foreldre/Foresatte,*

For cirka ti dager siden sendte jeg ut et spørreskjema **”Utfordringer for familier som har barn med autisme, med fokus på samarbeidet med tjenesteapparatet og på familiens sosiale kontaktnett”**.

Jeg har fått inn en del spørreskjemaer tilbake, men håper at enda flere vil svare på det.

Jeg ber om dere svarer så fort som mulig.

På forhånd takk for hjelpen!

Med vennlig hilsen

Nadiya Konovalova

17.01.2008

Sendes til: Professor Liv Randi Opdal (veileder)

Postboks 1140 Blindern

0318 Oslo

e-mail: [l.r.opdal@isp.uio.no](mailto:l.r.opdal@isp.uio.no)



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## Appendix 7. Reminding Letter 3.

**”Utfordringer for familier som har barn med autisme, med fokus på samarbeidet med tjenesteapparatet og på familiens sosiale kontaktnett”.**

Dette purrebrevet går til alle aktuelle foreldre. Dersom dere allerede har sendt inn spørreskjemaet, ber jeg dere om å se bort fra dette brevet.

### *Påminnelse*

***Kjære Foreldre/Foresatte,***

For cirka ti dager siden sendte jeg et brev til dere og ba om at de som ikke hadde hatt anledning til å svare på spørreskjemaet kunne gjøre det. Jeg mangler fremdeles noen svar fra de som allerede satt seg villige til å delta i undersøkelsen. Jeg ber de som ikke har svart om å være så snill å fylle ut spørreskjemaer så fort som mulig og sende det til:

Professor Liv Randi Opdal (veileder)  
Postboks 1140 Blindern  
0318 Oslo  
e-mail: [l.r.opdal@isp.uio.no](mailto:l.r.opdal@isp.uio.no)

Spørreskjemaet er vedlagt denne henvendelsen.

På forhånd takk for hjelpen!

Med vennlig hilsen

Nadiya Konovalova

26.01.2008



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**Appendix 8. Questionnaire**

**UNIVERSITY OF OSLO  
DEPARTMENT OF SPECIAL NEEDS EDUCATION**

**QUESTIONNAIRE “CHALLENGES IN PARENTING A CHILD  
WITH AUTISM SPECTRUM DISORDER”**



Please return to:

Professor Liv Randi Opdal  
Department of Special Needs Education  
“Challenges in Parenting a Child with Autism Spectrum Disorder”  
P.O.Box 1140 Blindern  
0318 Oslo

Autumn 2007

“Challenges in parenting a child with Autism Spectrum Disorder, with focus on the family’s cooperation with different professionals and on the family’s sphere of social contacts.”

**A. General information:**

1. Which country do you originally come from?

.....

2. Are you male or female?

Male

Female

3. What is your year of birth?

.....

4. What is the highest level of your complete education?

.....

If needed, please explain

.....

5. Are you a two parent-family?

Yes

No

If wanted add some information

.....

6. How many children are there in your family all together?

.....

7. Are there other children in the family with special needs?

Yes

No

If yes, please, specify what kind of needs.

.....

The following questions concern your child with autism spectrum disorder.



8. Is your child male or female?

Male

Female

9. What is your child's year of birth?

.....

10. How long it is since your child was given the diagnoses?

.....

11. Does your child with autism spectrum disorder have medical problems in addition to the given diagnoses?

Yes

No

If yes, please specify what kind of problems.

.....

12. Does your child have an Individual Educational Plan?

Yes

No

The rest of the questionnaire contains statements which I would like you to read and assess. There are no right or wrong answers and your point of view is important.  
Please circle **only one alternative** which is relevant to you.

**B. Cooperation with different professionals:**

The term “professionals” here refer to kindergarten teachers, teachers, after-school teachers, psychologists, medical doctors and other assistant personnel.

**Professional support:**

13. “If my child needs help I need to have a professional to turn to.”

Very important      Rather important      Rather unimportant      Very unimportant

14. “I do have a professional to turn to if my child needs help.”

Yes                      Partially                      No

Please specify

.....

15. “Information about my child’s educational or therapeutic progress should be given to me”

Very important      Rather important      Rather unimportant      Very unimportant

16. “I do get information about my child’s progress.”

Yes                      Partially                      No

Please specify.....

17. “Different professionals have to agree among themselves on the best way to help my child.”

Very important      Rather important      Rather unimportant      Very unimportant

18. “The information about my child’s progress should be given in a language I understand.”

Very important      Rather important      Rather unimportant      Very unimportant

19. “I do get the information from the professionals in an understandable language.”

Yes                      Partially                      No

20. "Educational and therapeutic services appropriate for my child should be continuous."

Very important	Rather important	Rather unimportant	Very
unimportant			

21. "Professionals working with my child should understand both the needs of my child and my family."

Very important	Rather important	Rather unimportant	Very
unimportant			

22. "The professionals I cooperate with do understand the needs of my child as well as the needs of my family".

Yes	Partially	No
-----	-----------	----

23. "Complete information about the services of my community which are appropriate for my child should be given to me."

Very important	Rather important	Rather unimportant	Very
unimportant			

24. "I do get the complete information about the services of the community appropriate for my child".

Yes	Partially	No
-----	-----------	----

25. "Professionals I cooperate with should have experience with children with the same disability."

Very important	Rather important	Rather unimportant	Very
unimportant			

26. "Help in implementing Individual Education Plan goals should be given to me."

Very important	Rather important	Rather unimportant	Very
unimportant			

27. "I do get the help I need for implementing the Individual Education Plan's goals."

Yes	Partially	No
-----	-----------	----

28. "Weekend and after school activities should be provided to my child by professionals."

Very important      Rather important      Rather unimportant      Very unimportant

29. "My child is provided with weekend and after school activities by professionals"

Yes                      Partially                      No

Please specify.....

30. "I need honest answers to my questions from the professionals."

Very important      Rather important      Rather unimportant      Very unimportant

In the following section I want you to evaluate your cooperation with different professionals:

31. "I can describe my cooperation with teachers/kindergarten teachers as following":

I never contacted these professionals.

I contacted these professionals and did not get help.

I contacted these professionals and got help.

I contact these professionals every time I need help from him/her.

32. "I can describe my cooperation with medical doctors as following":

I never contacted these professionals.

I contacted these professionals and did not get help.

I contacted these professionals and got help.

I contact these professionals every time I need help from them.

33. "I can describe my cooperation with psychologists as following":

I never contacted these professionals.

I contacted these professionals and did not get help.

I contacted these professionals and got help.

I contact these professionals every time I need help from them.

34. "I can describe my cooperation with assistant personnel as following":

I never contacted these professionals.

I contacted these professionals and did not get help.

I contacted these professionals and got help.

I contact these professionals every time I need help from them.

35. Is there anything about the professional support which you would like to add?

.....  
 .....  
 .....

**Parental involvement in the process:**

36. "I need to be actively involved in the setting up of Individual Education Plan for my child."

Very important      Rather important      Rather unimportant      Very unimportant

37. "I am actively involved in the setting up of Individual Education Plan"

Yes                      Partially                      No

38. "I want to know if my opinions about the planning of my child's treatments and therapies (other than Individual Education Plan) are taken into consideration by the professionals."

Very important      Rather important      Rather unimportant      Very unimportant

39. "My opinions are considered when my child's activities (other than Individual Education Plan) are planned."

Yes                      Partially                      No

40. Is there anything you would like to add about your active parental involvement in the process of planning the activities and the activities themselves?

.....  
 .....  
 .....

**Emotional support from the professionals:**

41. "The decisions I make concerning my child should be approved by professionals."

Very important      Rather important      Rather unimportant      Very unimportant

42. "Professionals do give me feedback about the decisions I make."

Yes                      Partially                      No  
Please specify.....

43. "Professionals should help me to remain hopeful about my child's future."  
Very important      Rather important      Rather unimportant      Very unimportant

44. "Professionals do help me to remain hopeful about my child's future."  
Yes                      Partially                      No

45. "I need professionals for sharing my hopes and fears concerning my child."  
Very important      Rather important      Rather unimportant      Very unimportant

46. "I do have professionals with whom I'm able to share my hopes and fears."  
Yes                      Partially                      No

47. Is there anything you would like to add about the emotional support you  
get from the professionals?

.....  
.....  
.....

### C. Social contacts

48. "I would like to have time to spend with my friends outside my family."  
Very important      Rather important      Rather unimportant      Very unimportant

49. "I do have free time which I can spend with my friends outside my  
family."

Yes                      Partially                      No  
Approximately how many hours per week.....

50. "I want to have more time to spend with my friends outside my family."  
Very important      Rather important      Rather unimportant      Very unimportant

Please specify if needed.....

51. "My family members should understand my child's problems."  
Very important      Rather important      Rather unimportant      Very unimportant

52. "My family members do understand my child's problems."

Yes

Partially

No

53. "I need to have a network of parents who have a child with the same disorder."

Very important

Rather important

Rather unimportant

Very unimportant

54. "I do have a network of parents who have a child with the same disorder."

Yes

Partially

No

55. "I need a network of friends who understand the ramifications of the disorder my child has and who can support me in my parenting challenges."

Very important

Rather important

Rather unimportant

Very unimportant

56. "I do have a network of friends who understand the ramifications of the disorder my child has and who are supportive of me in facing the challenges of parenting a child with an autism spectrum disorder."

Yes

Partially

No

57. "I want my child to have his/her own friends."

Very important  
unimportant

Rather important

Rather unimportant

Very

58. "My child does have his/her own friends."

Yes

Partially

No

59. "I want my child to have different types of social contacts/activities outside the family."

Very important  
unimportant

Rather important

Rather unimportant

Very

60. "My child does have activities outside the family"

Yes

Partially

No

If yes please specify.....

61. "Occasionally I need someone from my family to take my responsibilities for me"

Very important      Rather important      Rather unimportant      Very unimportant

62. "I do have a family member who can occasionally take my responsibilities from me if I need it".

Yes                      Partially                      No

63. Is there anything about the social contacts you would like to add?

.....  
.....  
.....

64. Please write additional comments about the questions in the questionnaire

.....  
.....  
.....  
.....  
.....  
.....

THANK YOU!

Please return to:

Liv Randi Opdal

Department of Special Needs Education

"Challenges in Parenting a Child with Autism Spectrum Disorder"

P.O.Box 1140 Blindern

0318 Oslo

*If you an addition would be willing to be interviewed about the same topic,  
please contact me by tel: 93874176 / 22187501 or by email:  
nadiyak@student.uv.uio.no*



## Appendix 9. Frequency tables.

**Table 1. Which country do you originally come from**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Norway	9	60,0	60,0	60,0
	Sri Lanka	3	20,0	20,0	80,0
	Ghana	1	6,7	6,7	86,7
	Russia	1	6,7	6,7	93,3
	Pakistan	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 2. Are you male or female**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	female	8	53,3	53,3	53,3
	male	5	33,3	33,3	86,7
	both of the parents	2	13,3	13,3	100,0
	Total	15	100,0	100,0	

**Table 3. What is your year of birth**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1970	3	20,0	20,0	20,0
	1960	2	13,3	13,3	33,3
	1962	2	13,3	13,3	46,7
	1953	1	6,7	6,7	53,3
	1959	1	6,7	6,7	60,0
	1969	1	6,7	6,7	66,7
	1966	1	6,7	6,7	73,3
	1972	1	6,7	6,7	80,0
	1967	1	6,7	6,7	86,7
	1973	1	6,7	6,7	93,3
	1957	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 4.What is the highest level of your complete education**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	high school	7	46,7	46,7	46,7
	university/college	7	46,7	46,7	93,3
	secondary education	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 5.Does you child live with both parents**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	6	40,0	42,9	42,9
	with the mother	3	20,0	21,4	64,3
	lives at other place/institution	3	20,0	21,4	85,7
	no	1	6,7	7,1	92,9
	with the father	1	6,7	7,1	100,0
	Total	14	93,3	100,0	
Missing	missing out	1	6,7		
Total		15	100,0		

**Table 6.How many children are there in your family all together**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2	5	33,3	33,3	33,3
	1	5	33,3	33,3	66,7
	3	4	26,7	26,7	93,3
	4	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 7.Are there other children in the family with special needs**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	3	20,0	20,0	20,0
	no	12	80,0	80,0	100,0
	Total	15	100,0	100,0	

**Table 8.Is your child male or female**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	male	11	73,3	73,3	73,3
	female	4	26,7	26,7	100,0

Total	15	100,0	100,0
-------	----	-------	-------

**Table 9.What is your child's year of birth**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1996	3	20,0	20,0	20,0
1992	2	13,3	13,3	33,3
1997	2	13,3	13,3	46,7
1999	2	13,3	13,3	60,0
1998	2	13,3	13,3	73,3
1993	1	6,7	6,7	80,0
1990	1	6,7	6,7	86,7
1991	1	6,7	6,7	93,3
1994	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 10.How long is it since your child has been given a diagnoses**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 10	3	20,0	20,0	20,0
6	3	20,0	20,0	40,0
7	2	13,3	13,3	53,3
13	2	13,3	13,3	66,7
4	1	6,7	6,7	73,3
15	1	6,7	6,7	80,0
12	1	6,7	6,7	86,7
8	1	6,7	6,7	93,3
9	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 11.Does your child with autism spectrum disorder have medical problems in addition to the given diagnoses**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid no	10	66,7	66,7	66,7
yes	5	33,3	33,3	100,0
Total	15	100,0	100,0	

**Table 12.Does your child have an individual education plan**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	14	93,3	93,3	93,3
no	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 13.If my child needs help I have a professional to turn to**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	12	80,0	80,0	80,0
rather important	3	20,0	20,0	100,0
Total	15	100,0	100,0	

**Table 14.I do have a professional to turn to if my child needs help**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	9	60,0	60,0	60,0
partially	5	33,3	33,3	93,3
no	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 15.Information about my child's educational or therapeutic progress should be given to me**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	15	100,0	100,0	100,0

**Table 16.I do get information about my child's progress**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	12	80,0	80,0	80,0
partially	2	13,3	13,3	93,3
no	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 17.Different professionals have to agree among themselves on the best way to help my child**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	10	66,7	66,7	66,7
rather important	4	26,7	26,7	93,3

rather unimportant	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 18.The information about my child should be given in a language I understand**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	14	93,3	93,3	93,3
rather unimportant	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 19.I do get the information from the professionals in an understandable language.**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	13	86,7	86,7	86,7
partially	2	13,3	13,3	100,0
Total	15	100,0	100,0	

**Table 20.Educational and therapeutic services appropriate for my child should be continuous**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	15	100,0	100,0	100,0

**Table 21.Professionals working with my child should understand both the needs of my child and my family**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	15	100,0	100,0	100,0

**Table 22.The professionals I cooperate with do understand the needs of my child as well as the needs of my family**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	9	60,0	60,0	60,0
partially	6	40,0	40,0	100,0
Total	15	100,0	100,0	

**Table 23.Complete information about the services of my community which are appropriate for my child should be given to me**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	14	93,3	93,3	93,3
rather important	1	6,7	6,7	100,0

Total	15	100,0	100,0
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**Table 24.I do get the complete information about the services of the community appropriate for my child**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	4	26,7	26,7	26,7
partially	6	40,0	40,0	66,7
no	5	33,3	33,3	100,0
Total	15	100,0	100,0	

**Table 25.Professionals I cooperate with should have experience with children with the same disability**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	14	93,3	93,3	93,3
rather important	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 26.Help in implementing individual education plan's goals should be given to me**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	12	80,0	80,0	80,0
rather important	3	20,0	20,0	100,0
Total	15	100,0	100,0	

**Table 27.I do get the help I need in implementing the Individual Education Plan's goals**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	9	60,0	64,3	64,3
partially	3	20,0	21,4	85,7
no	2	13,3	14,3	100,0
Total	14	93,3	100,0	
Missing missing out	1	6,7		
Total	15	100,0		

**Table 28.Weekend and afterschool activities should be provided to my child by the professionals**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	8	53,3	57,1	57,1
rather important	5	33,3	35,7	92,9
rather unimportant	1	6,7	7,1	100,0
Total	14	93,3	100,0	
Missing missing out	1	6,7		
Total	15	100,0		

**Table 29. My child is provided with weekend and afterschool activities by professionals**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	2	13,3	14,3	14,3
partially	6	40,0	42,9	57,1
no	6	40,0	42,9	100,0
Total	14	93,3	100,0	
Missing missing out	1	6,7		
Total	15	100,0		

**Table 30. I need honest answers to my questions from the professionals**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	15	100,0	100,0	100,0

**Table 31. I can describe cooperation with teachers/kindergarten teachers as following**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid I never contacted these professionals	2	13,3	13,3	13,3
I contacted these professionals and did not get help	1	6,7	6,7	20,0
I contacted these professionals and got help	4	26,7	26,7	46,7
I contact these professionals every time I need help from them	8	53,3	53,3	100,0
Total	15	100,0	100,0	

**Table 32. I can describe cooperation with medical doctors as following**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid I never contacted these professionals	1	6,7	6,7	6,7
I contacted these professionals and did not get help	2	13,3	13,3	20,0
I contacted these professionals and got help	5	33,3	33,3	53,3
I contact these professionals every time I need help from them	7	46,7	46,7	100,0
Total	15	100,0	100,0	

**Table 33. I can describe cooperation with psychologists as following**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I never contacted these professionals	6	40,0	40,0	40,0
	I contacted these professionals and did not get help	1	6,7	6,7	46,7
	I contacted these professionals and got help	6	40,0	40,0	86,7
	I contact these professionals every time I need help from them	2	13,3	13,3	100,0
	Total	15	100,0	100,0	

**Table 34. I can describe cooperation with assistan personell as following**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I contacted these professionals and did not get help	2	13,3	13,3	13,3
	I contacted these professionals and got help	5	33,3	33,3	46,7
	I contact these professionals every time I need help from them	8	53,3	53,3	100,0
	Total	15	100,0	100,0	

**Item 35 is an open-ended question**

**Table 36. I need to be actively involved in the setting up of Individual Education Plan for my child**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	10	66,7	66,7	66,7
	rather important	3	20,0	20,0	86,7
	rather unimportant	1	6,7	6,7	93,3



very unimportant	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 37. I am actively involved in the setting up of Individual Education Plan**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	11	73,3	73,3	73,3
partially	3	20,0	20,0	93,3
no	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 38. I want to know if my opinions about the planning of my child's treatments and therapies are taken into consideration by the professionals**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	12	80,0	80,0	80,0
rather important	3	20,0	20,0	100,0
Total	15	100,0	100,0	

**Table 39. My opinions are considered when my child's activities are planned**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	10	66,7	66,7	66,7
partially	4	26,7	26,7	93,3
no	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 40. Is there anything about the active parental involvement you would like to add**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid positive	1	6,7	25,0	25,0
critique	3	20,0	75,0	100,0
Total	4	26,7	100,0	
Missing missing out	11	73,3		
Total	15	100,0		

**Table 41. The decisions I make concerning my child should be approved by the professionals**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid very important	9	60,0	60,0	60,0
rather important	5	33,3	33,3	93,3
rather unimportant	1	6,7	6,7	100,0
Total	15	100,0	100,0	

**Table 42. Professionals do give me feedback about the decisions I make**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	10	66,7	71,4	71,4
	partially	4	26,7	28,6	100,0
	Total	14	93,3	100,0	
Missing	missing out	1	6,7		
Total		15	100,0		

**Table 43. Professionals should help me to remain about my child's future.**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	14	93,3	93,3	93,3
	rather important	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 44. Professionals do help me to remain about my child's future**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	10	66,7	66,7	66,7
	partially	3	20,0	20,0	86,7
	no	2	13,3	13,3	100,0
	Total	15	100,0	100,0	

**Table 45. I need professionals for sharing my hopes and fears concerning my child**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	12	80,0	80,0	80,0
	rather important	3	20,0	20,0	100,0
	Total	15	100,0	100,0	

**Table 46. I do have professionals with whom I'm able to share my hopes and fears**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	8	53,3	57,1	57,1
	partially	6	40,0	42,9	100,0
	Total	14	93,3	100,0	
Missing	System	1	6,7		
Total		15	100,0		

Item 47 is an open-ended question

**Table 48. I would like to have time to spend with my friends outside my family**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	10	66,7	66,7	66,7
	rather important	4	26,7	26,7	93,3
	very unimportant	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 49. I do have free time I can spend with my friends outside my family**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	6	40,0	40,0	40,0
	partially	4	26,7	26,7	66,7
	no	5	33,3	33,3	100,0
	Total	15	100,0	100,0	

**Table 50. I want to have more time to spend with my friends outside my family**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	7	46,7	46,7	46,7
	partially	3	20,0	20,0	66,7
	no	3	20,0	20,0	86,7
	4	2	13,3	13,3	100,0
	Total	15	100,0	100,0	

**Table 51. My family members should understand my child's problems**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	14	93,3	93,3	93,3
	rather important	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 52. My family members do understand my child's problems**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	8	53,3	53,3	53,3
	partially	5	33,3	33,3	86,7
	no	2	13,3	13,3	100,0
	Total	15	100,0	100,0	

**Table 53. I need to have a network of parents who have a child with the same disorder**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	4	26,7	26,7	26,7
	rather important	8	53,3	53,3	80,0
	rather unimportant	2	13,3	13,3	93,3
	very unimportant	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 54. I do have a network of parents who have a child with the same disorder**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	3	20,0	20,0	20,0
	partially	6	40,0	40,0	60,0
	no	6	40,0	40,0	100,0
	Total	15	100,0	100,0	

**Table 55. I need a network of friends who understand the ramifications of the disorder my child has and who can support me in my parenting challenges**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	6	40,0	40,0	40,0
	rather important	6	40,0	40,0	80,0
	rather unimportant	2	13,3	13,3	93,3
	very unimportant	1	6,7	6,7	100,0
	Total	15	100,0	100,0	

**Table 56. I do have a network of friends who understand the ramifications of the disorder my child has and who are supportive of me in facing the challenges of parenting a child with ASD**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	4	26,7	26,7	26,7
	partially	7	46,7	46,7	73,3
	no	4	26,7	26,7	100,0
	Total	15	100,0	100,0	

**Table 57. I want my child to have his/her own friends**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	5	33,3	35,7	35,7
	rather important	5	33,3	35,7	71,4
	rather unimportant	2	13,3	14,3	85,7
	very unimportant	2	13,3	14,3	100,0
	Total	14	93,3	100,0	

Missing	missing out	1	6,7		
Total		15	100,0		

**Table 58. My child does have his/her own friends**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	partially	5	33,3	35,7	35,7
	no	9	60,0	64,3	100,0
	Total	14	93,3	100,0	
Missing	missing out	1	6,7		
Total		15	100,0		

**Table 59. I want my child to have different types of social contacts/activities outside the family**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	12	80,0	80,0	80,0
	rather important	3	20,0	20,0	100,0
	Total	15	100,0	100,0	

**Table 60. My child does have activities outside the family**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	4	26,7	26,7	26,7
	partially	8	53,3	53,3	80,0
	no	3	20,0	20,0	100,0
	Total	15	100,0	100,0	

**Table 61. Occasionally I need someone from my family to take my responsibilities for me**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very important	6	40,0	46,2	46,2
	rather important	4	26,7	30,8	76,9
	rather unimportant	2	13,3	15,4	92,3
	very unimportant	1	6,7	7,7	100,0
	Total	13	86,7	100,0	
Missing	missing out	2	13,3		
Total		15	100,0		

**Table 62. I do have a family member who can occasionally take my responsibilities from me if I need it.**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	4	26,7	30,8	30,8
	no	9	60,0	69,2	100,0
	Total	13	86,7	100,0	
Missing	missing out	2	13,3		

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Total	15	100,0		
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Item 63 is an open-ended question

Item 64 is an open-ended question